MOBILE-EYES FOR CHANGE

Immersive Reality Technologies and the Design of Human Services:

(A CASE STUDY IN AUTISM SPECTRUM DISORDER)

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the degree of Master of Design in Strategic Foresight & Innovation
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DECLARATION

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ABSTRACT

Virtual Reality (VR) is a nascent technology platform that through the use of headsets immerses users into feeling as though they are transported to a new world (or space) with a sense of presence and the fidelity of real life. The VR industry is expected by many to disrupt how we consume and experience media as well as reimagine countless industries including filmmaking, gaming, entertainment, education and healthcare.

The rise of immersive reality technology platforms like VR can be juxtaposed with the rising state of crisis that exists in the Autism Services System (ASD) in Ontario for both youth and adults. Currently in Ontario there is a complex system of services where many individuals need various degrees of support and treatment with few and difficult to navigate supports available for some and not for all. This includes assistance for aging adults with ASD and other developmental disabilities. The core of human services systems such as Ontario's ASD system are the lived experiences of families/caregivers who navigate multiple services/ supports and provide care for their diagnosed loved ones. This major research project will explore the potential for VR technology to play a role in capturing and sharing the lived experience of families\caregivers to impact the design of services within human services systems in Ontario through the lens of the ASD system. The project will conclude by offering implications and directions for future research.

Keywords: Virtual Reality, Autism, Learning, Innovation, Documentary, Disruption, Service Design, Futures

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I am humbled and forever grateful for the many people who supported me on this journey. Thank you for walking beside me in my darkest hours on this path and also running ahead just enough whenever I needed to help me see the light.

Dear Riel,
May this body of work inspire you to know that your imagination will always be the engine of resilience in life. Always remember that adversity is a gift that brings power and wisdom
You are my heart.

To my mother and brother,
You are my heroes and I will forever draw upon your strength.

DEDICATION

I dedicate this project to any family, parent, caregiver or advocate who feel their voices have either not been heard or not heard loud enough when supporting a loved one in need. I share your despair and am inspired by your resilience, strength, sacrifice and courage. I also dedicate this to the human services professionals and policy public servants in Ontario who work tirelessly through the windstorms of bureaucracy to try and make a positive impact in the lives of individuals they support and their families. I share your burden and passion.

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PREFACE

A cathartic exploration of my experiences navigating the Ontario social services system as both a parent and caregiver to individuals diagnosed with autism spectrum disorder was the catalyst that led me to join the Strategic Foresight and Innovation (SFI) program. My hope was that the program would guide me toward the necessary tools and temperament to create a meaningful solution in a system rife with seemingly impenetrable challenges. Yet before beginning this journey, I knew that my creative ambition and the complexity of my experiences (both professional and personal) would potentially create untenable assumptions based on my own biases. The concern was that if left unchecked, biases and assumptions would undermine and cripple any subjective narrative I was trying to construct. The net effect I feared would be limiting this project to be just an introspective exploration. Instead, I aim to produce a scholarly contribution in pursuit of a germane and actionable innovation. These challenges were the *Goliath* (1 Samuel 17:1–7 Old Testament Version I) I faced. It was not until after many months of stumbles and agonizing confidence-rattling moments that I finally recognized an unforgettable truth. Trusting my path and embracing an iterative, creative process -- no matter how punishing -- was the only way possible. This is when I became *David*(1 Samuel 17:1–7 Old Testament Version I). The central idea behind this project is to explore the potential of human services systems embracing newer forms of technology as tools to support enhanced understanding of the lived experiences of those they support. Thus, potentially creating more responsive services for individuals and their families/caregivers. My hypothesis also includes a belief that human services systems all have the same fundamental challenge of effectively understanding and utilizing the broad lived experiences of those they support along with their families/caregivers. Therefore, instead of investigating a broad scope of systems this project will be exploratory in nature focusing on the ASD system in Ontario.

1. WHO IS THIS FOR?

'Nobody really knows what I go through"

– A mother when describing her interactions in the ASD system as a parent supporting an aging adult.

"We're not really good at that."

– A policy analyst working in Ontario in response to a question asking if the ASD system in Ontario acknowledges a need to obtain more diverse voices as possible to inform service design. Not just the individuals that raise their hands higher and stomp their feet loudest.

This topic was inspired by the struggles of families and caregivers as well as those entrusted with designing services in Ontario's ASD System.

RESEARCH QUESTION

How might the recording and viewing of a Virtual Reality experience play a role in giving family/caregiver lived experiences a greater presence when designing services and/or policy in the autism services system in Ontario in the near future?

2. SYSTEM SPOTLIGHT: THE AUTISM SERVICES SYSTEM IN ONTARIO

HISTORICAL OVERVIEW

Autism Spectrum Disorder (ASD) can be defined as a

> lifelong neurological disorder that affects the way a person communicates and relates to the people and world around them. ASD can affect behaviour, social interactions, and one's ability to communicate verbally. ASD is a spectrum disorder, which means that while all people with ASD will experience certain difficulties, the degree to which each person on the spectrum experiences these challenges will be different (Autism Ontario, 2016).

Additionally, Autism Ontario (2016) also states that "1 in 94 Canadian children are diagnosed with autism and there are currently 135,000 individuals in Ontario living with an ASD diagnosis as of 2016." In another finding, Stoddart et al. (2013) estimated that up to "93,412 adults with ASD are living in Ontario." Since ASD is a disorder that currently stretches across one's lifespan, there are a multitude of settings in Ontario where interventions and supports are required (depending on need) to support an individual with ASD and their families. These settings include:

- Early intervention
- Child Care Settings
- Secondary and Post-Secondary Schools

- Transition to Adulthood
- Employment
- Long-Term Care

The various interactions and scenarios that manifest during the above listed settings for individuals with ASD and their families has meant historical challenges within Ontario. These challenges include supporting the full range of needs that individuals on the spectrum have and the issues associated with coordinating involvement of adjacent human services systems (e.g. Mental Health Services and Education).

As a result, the introduction of these settings and service systems creates a web of complexity for all system actors including individuals with ASD and their families. According to Autism Ontario (2016) “This [challenge] can sometimes result in unintended conflicts with community at large; it can lead to engagement with the mental health sector, as well as criminal and family justice systems.” In response, Ontario has attempted multiple strategies including adopting an approach where early intervention for children with special needs such as ASD is seen as the key to long-term success.

According to the Ontario Ministry of Children and Youth Services (2016)

> Ontario’s Special Needs Strategy connects children and youth to the services they need as early as possible and improve the service experience of families. Trained providers will have a new developmental screening process for children in the preschool years. They will screen for potential risks to the child’s development as early as possible.

As a result, the core intervention services for children with ASD in Ontario include:

- Communication Based Interventions
- Social Skills Development
- And Behaviour Based Interventions

The province provides two main types of services for children; Intensive Behavioral Therapy (IBI) and Applied Behavioural Analysis (ABA). The differences between the two services are articulated in the Ontario *Government's Autism Parent Resource Kit* (2013) as follows;

> ABA uses methods based on scientific principles of learning and behaviour to build useful modes of behaviour while reducing problematic ones. IBI is an application of ABA to teach new skills in an intensive format (approximately 20 or more hours per week). Primarily, a one to one teaching ratio is required (p.15).

There have been challenges within Ontario's system of providing enough effective intervention supports for those in need and their families. More specifically, the issue of wait times for IBI and ABA supports has been a major contributor to the current pressure points within the system. A closer look at the staggering wait time numbers for these therapies reveal the extent of the problem. The Office of the Auditor General of Ontario (2013) noted that

> Over the last five years, the number of IBI spots has remained relatively constant at 1,400 while the number of children waiting for IBI services increased by 23%.This has led to a situation where families with financial

> means can acquire private services for their child while they wait for government funded services, but other families are unable to do so. In addition, some children with persistent parents were able to access services more quickly than others who had been placed on the waitlist before them (p.55).

In 2015, The Toronto Star (2015) presented an even bleaker picture when they revealed the Ontario waiting lists in 2014-15 for ABA and IBI topped 16,158 childrenIn addition, Piccininni and Penner (2016) state that the “average wait time for this program is 2.7 years and further that there has been no analysis modelinglifetime cost-effectiveness of wait time reduction for IBI (p.19).” Demand for these services is also an ever growing challenge.

According to The Office of the Auditor General of Ontario (2013)

> It is up to service agencies to decide how to allocate ministry funding between the direct service option and the direct funding option, and wait times for IBI services can differ between the two. The agencies involved in providing IBI services identified that it is a challenge to find the appropriate mix of spots for each delivery option because of the pressure to alter their clinical capacity to meet ever-changing demand (p.61).

The literature reviewed also reveals a consistent theme that the system currently does not have the instruments to fully eliminate its barriers. For example, The Office of the Auditor General of Ontario’s (2013) results indicate that “the ministry did not collect information that would help it monitor compliance with program guidelines and evaluate program effectiveness (p. 79)”. In addition to this, multiple non-ministry authored sources illuminate the need for changes within the system. According to The Select Services Committee (2014)

> There should be a fundamental shift in the way that support is offered to people with developmental disabilities. Rather than the current approach of forcing people to choose from a limited slate of options available through direct funding and agency-based support, we believe that every person should be entitled to an individualized life plan customized to meet their specific needs, including cultural and linguistic needs where relevant. Individualized life plans enable people to design the support model they feel provides them with the best opportunity for inclusion (p.8)".

Historically, like many other jurisdictions; Ontario has also been struggling to provide a cohesive infrastructure to support individuals with ASD as they transition from childhood to adulthood and ultimately becoming seniors. According to Maich and Hall (2016) in their book entitled: *Autism Spectrum Disorder in the Ontario Context: An Introduction*.

> In Ontario, advocacy for adults with ASD continues to be an ongoing concern. Difficulties stem from a lack of funding, and include a lack of specialized services that meet the needs of those with ASD, all entangled with many potential comorbid mental health needs (p. 263).

As a result, this could potentially add to the strain and lived experiences of families/caregivers face when supporting a loved one with ASD.

This point is emphasized when Boshoff et al. (2016) state that “The complexity of ASD and its subsequent impact on a child is matched by the multifaceted effects on their parents and family.”

DEFINITION OF THE TERM FAMILY

There are various cross societal and cultural standards for the word *family.* As a result, various interpretations and meanings exist. In response to this, a summary of key literature from analogous social systems will be presented to provide a foundation of inquiry. The Mental Health Commission of Canada (MHCC, 2015) defines family caregivers as “all those in the circle of care, including family members and other significant people who provide unpaid support to an individual” (p.1). According to the Centre for Addiction and Mental Health (CAMH) (2015), other definitions abound throughout the literature, but the key principles of enduring commitment, a broad definition of relationship and those whom the client/patient identifies as significant are important factors for consideration (p. 7).To ensure an inclusive lens is applied to this project the term *parents* and *family* will be used broadly in the spirit of these definitions and used in conjunction with the term *caregiver*.

FAMILY/CAREGIVER CHALLENGES IN ONTARIO'S ASD SYSTEM

Like most social service systems in Ontario, engagement within the ASD service system is a web of complexity, hope, promise and frustration. At the intersection of discovering a cause and providing effective support for those with a diagnosis is a system of individuals who fill multiple roles such as experts, researchers, administrators, direct service workers, policy makers, advocacy groups, family support coordinators and more. Also an integral part of this system, are families/caregiver(s) in which many of whom are managing multiple roles. These roles include being providers, system navigators, and in some cases treatment/intervention implementers. This project asserts that parent(s)/caregiver(s) are in essence, the heart of the system. This is based on the fact that every successful service or failed communication is both influenced and determined through the prism of their lived experience(s). The past decade has brought a multitude of warnings from various sources about Ontario's ASD system. These warnings include unbearable wait times for children to receive IBI therapy and a lack of supports for adults with ASD. In its survey of 1,730 caregivers the Canadian Autism Spectrum Disorders Alliance (CASDA,2014) reported in 2014 that "a majority of them (91%) responded by saying the barrier they faced the most when trying to access services was a lack of resources(p. 67)." Further to this, The Select Services Committee (2014) states that:

> Families asked for better communication from the MCSS (Ministry of Community and Social Services) and DSO (Developmental Services

> Ontario) offices about what services and funding are available, noting that other parents are their primary sources of information. An agency representative said that families need help to navigate the system, explaining that most families do not know what they need, are not aware they can ask for assistance, and require advice on how to utilize the few services that are available. One mother told the committee that younger parents like her are also struggling: We can't work, be parents and be the support workers of our children.

Analysis of this literature provided signals that could show consistency of program design that honours lived experiences is indeed a gap but not a main priority within the system. The common and familiar narrative found in the literature (both in the child and adult ASD systems) points to a common theme that parents and caregivers of individuals with ASD typically experience high levels of stress and experience crisis more than families and caregivers who are not actively supporting an individual with ASD.

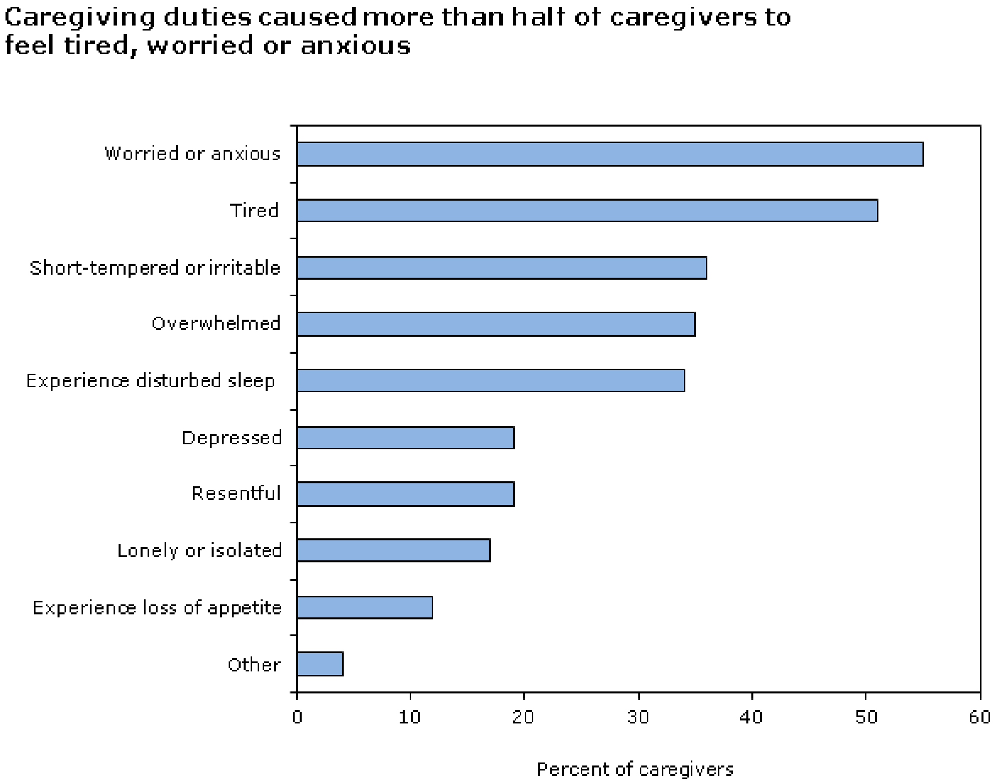
According to Weiss, Wingsiong, and Lunksy (2014)

> Parents of individuals with autism spectrum disorders (ASD) often report high levels of stress and mental health problems, associated with the challenges of caring for individuals with complex needs and with navigating multiple service sectors across the life course. Parents usually have the major obligation of caring for their child (which includes management of problematic behaviors) and balancing associated stress while overseeing the wellbeing of the rest of their family.

Further evidence of caregiver stress is found in an analytical paper authored by Maire Sinha on behalf of Statistics Canada entitled *Spotlight on Canadians: Results from the General Social Survey: Portrait of Caregivers, 2012 (Statistics Canada ,2013)*

which identified the following health consequences of caregiving.

Figure 1: Evidence of Caregiver Stress (STATSCAN, 2013)



Source:
Source: Statistics Canada (2013). Spotlight on Canadians: Results from the General Social Survey. Portrait of Caregivers (2012). Retrieved from
http://www.statcan.gc.ca/pub/89-652-x/89-652-x2013001-eng.htm

This study also found that caring for those with developmental disabilities takes most time. According to Statistics Canada (StatsCan) (2013) certain health conditions required more hours of care. This was the case for developmental disabilities or disorders, where 51% of these caregivers supporting these individuals were spending at least 10 hours a week providing help. Parents and caregivers must balance providing care and navigating interactions with social services system(s) on behalf of an individual with ASD. In doing, so they will face a range of personal experiences and circumstances that are as diverse and complex as the system itself. Personal circumstances will include but not be limited to cultural practices/norms, income, living arrangement, employment, location/region, household/dwelling characteristics. This vast range of personal circumstances can also be compounded by other caregiving and professional responsibilities in their life. Also according to StatsCan (2013)

> 28% of caregivers in Canada could be considered “sandwiched” between caregiving and childrearing, having at least one child under 18 years living at home. A review of literature that uncovered the experiences of families and caregivers supporting adults with ASD was also completed.

In 2016, the Office of the Ombudsman of Ontario (2016) released a report entitled *Nowhere to Turn: Investigation into the Ministry of Community and Social Services’ (MCSS) response to situations of crisis involving adults with developmental disabilities.* This report included 1436 complaints and unveiled a multitude of challenges navigating the adult developmental disabilities system including the Autism system. The report notes that

> The process for accessing supports and services in the developmental services sector is complex, multi-layered, and inconsistent across the province. The 1,436 individuals, families, caregivers, and other stakeholders we heard from during this investigation were often bewildered by the developmental services system and confused by or oblivious to the distinctions amongst its various parts. Many were discouraged by interminable wait list delays and desperate for help. Some were on the brink of crisis; others firmly in its midst (p. 38).

This affirms Belkin's (2010) fundamental point when he asserts,
"when we talk about autism, we tend to talk about children and ways that their parents can help. But children grow, and the parents of autistic children become parents of autistic adults, a role that is less defined and less discussed".

This report also highlighted 60 recommendations that were all accepted by the ministry. To acknowledge the gap with parent/caregiver experience with adults Ontario's Deputy Minister for the Ministry of Community and Social Services responded by creating a document entitled, *Ministry of Community and Social Services (MCSS) Response to the Preliminary Ombudsman's Report: Situations of crisis involving adults with Developmental Disabilities* (Menard,2016). This letter stated that the Ministry of Community and Social Services is working with the developmental services sector to learn more about individual and family experiences and to identify changes that could be made to better support them and avoid crisis situations. In addition, the CASDA (2014) accounted for the professional perspective on family experience. In a recent survey, professionals highlighted the following about families.

> A focus on parents and family members was the most prominent of all their comments. Their comments were also presented in order of importance and the top choice was parent support. This is significant because it provides evidence that family experiences are not part of the current design process and it is acknowledged by professionals. Also presented by the professionals in this survey, but not represented in the comments of either the Caregivers or individuals with ASD's, were the challenges associated with linguistic and cultural diversity. This issue merits further exploration in light of the relatively low level of diversity identified among the Caregiver respondents (p, 35).

This lead to further exploration in the literature to investigate the potential underrepresentation of immigrant families experiences in the design of services. According to King, Lindsay et al. (2011)

> There is a large gap in our knowledge of the ways service organizations and systems respond to the needs of various immigrant populations. Research is needed to simply describe the service integration efforts that have been made to deal with barriers to awareness, access, and use and to uncover effective practices for immigrant families raising a child with a disabling condition (p.10).

The potential for access barriers for some families could cause more strain and gaps in the ASD system. Further to this, potential alienation and lack of supports for families/caregivers may make them and their loved ones with ASD more at risk to cascade into other human services systems such as Mental Health Services and the Justice System.

3. GENERAL REVIEW OF FAMILY/CAREGIVER LIVED EXPERIENCE LITERATURE

The wide range of family/caregiver experiences include a combination of acknowledging the following factors:

- Resilience & Sense Making
- Cultural considerations,
- Socio-economic factors.
- Advocacy

The following section will summarize key findings from reviewing general literature most applicable to this project.

RESILIENCE AND SENSE MAKING

The research uncovered two distinct approaches and findings with respect to this topic. There appears to be a tension that exists based on the severity of the diagnosis and the sense-making process of families/caregivers. Bayat (2007) indicates that

> making meaning out of diversity is known as a key process in family resilience. They found that families often reflected about what having a

> child with autism meant for them. Resilient families often make positive meaning out of adversity. The families studied not only made positive meaning of their child's disability, they also articulated many contributions and lessons learned as a result of disability. Families' meaning-making frequently resulted in a changed world view to a positive outlook on life in general, and an appreciation of smaller daily gifts and accomplishments in specific (p.710).

In addition, Bayat went on to add that

> Working with family's needs to capture the whole experience of families, and not just the negative experiences. Service providers who interface with families of children with disabilities can communicate to them a conviction that these families can be resilient, the same way they could communicate a negative conviction. This could give families a more positive outlook and hope (P, 711).

It is important to also highlight that the various literature reviewed also seemed to focus on capturing and articulating the stress and adjustment issues families face. King, Lindsay et al. (2011), reinforced that the research tends to adopt a narrow perspective of the child with autism where the child is viewed as a "…stressor testing parents' ability to cope and negatively influencing their psychological well-being" (p.20).

CULTURAL CONSIDERATIONS

The literature also referenced the importance of understanding the experiences of cultural diversity including norms and customs. According to King, Lindsay et al. (2011)

> There is a widespread tendency of cultural minorities to avoid engaging help. This is the result of many factors including: unfamiliarity with systems, lack of knowledge of services, perceptions of the roles of service providers and families, communication issues, culturally incongruent service delivery systems and service providers' assumptions and lack of understanding of culturally-influenced attitudes, beliefs and behaviours (p.35).

The importance of highlighting the issue of diversity is highlighted by an examination into Ontario's demographic trends which provide signals and trends for how important cultural considerations are for the future of any human services system in Ontario. According to the 2011 National Household Survey by Statistics Canada (2011), in the years between 2006 and 2011, Ontario's visible minority population increased nearly five times faster than the population as a whole (19.5% vs. 4.0%). The importance of this issue is compounded when Dyches, et al. assert that "they [Families] were discouraged that little information regarding how multicultural families adapt to raising a child with autism was available and that it warranted further investigation (2004)."

ADVOCACY

Also key to understanding the family/caregiver experience is the concept of advocacy including its complexities as well as its inherent benefits and challenges. In their 2016 study conducted with 532 parents/caregivers and a comprehensive review of 24 studies entitled, Parents' voices: ‘why and how we advocate’ Boshof, et al. (2016) proposed through their analysis that the full experience of parent advocacy for a child with ASD is viewed through 2 core concepts. These concepts are the challenges and benefits of advocacy.

The Challenges of Advocacy (Boshoff, et al. 2016)

- A life-long, persistent and all-encompassing challenge
- Advocacy is a parental coping strategy
- Advocacy involving working to create a future
- Ongoing process of understanding, facilitating and balancing the child's and own needs
- Advocacy as a part of parents' multiple roles, while juggling the associated responsibilities
- Isolation versus support
- The personal impacts of advocacy

Benefits of Advocacy

According to Phelps *et al.* (2009), “parents' personal benefits achieved through advocacy were described as a sense of altruism being able to vent” (Dreuth Zeman *et al*. 2011), finding support (Hoogsteen & Woodgate 2013) and having a positive impact on one's own mental health and employment opportunities

(Markoulakis *et al.* 2012). In addition Boshoof et al. (2016) assert that advocacy facilitated a transformational process for many parents, enabling empowerment for them to be able to take actions (e.g. in obtaining access to services). The importance of understanding the factors and themes introduced by Boshof et al. (2016) about family advocacy is that they provide further evidence on the complex nature of parent/caregiver experiences. Thus, introducing the argument that understanding these themes and enabling various methods to capture complex lived experiences can better support the design of services to be more responsive to the needs of parents/caregivers. It is also important to emphasize the barriers that exist in becoming a strong advocate. Jegatheesan et al. (2010) presented evidence that cultural background differences between family and ASD system service providers may be a barrier to strong advocacy. “They describe the implications of limited knowledge of rights, cultural clashes with therapists and parents feeling uncomfortable speaking out in public regarding their concerns.” In addition, Boshof et al. (2016) also articulate the point that “families with a higher socioeconomic and educational status were stronger advocates and more successful in accessing services for their children”. The importance of highlighting these barriers is that they can lead to a lack of diverse representation to shape the design of services. Thus, forcing the system to rely on assumptions and the experiences of those with the loudest voices.

4. THE ASSUMPTIONS MADE ABOUT FAMILY/CAREGIVER LIVED EXPERIENCES IN ONTARIO

The variance of experiences lived through by parents/caregivers presented in the previous sections was the impetus that led to an exploration of how Ontario's ASD system accounts for the vast range of family experiences during the design and/or implementation of services. Some guiding questions that framed my inquiry were:

1. What and whose perspectives are adopted when developing policy or designing services?
2. What, if any, assumptions exist in the design of programs and services that could potentially impact family/caregiver engagement?

The literature review resulted in findings that suggest either a possible lack of system capacity to account for the wide range of experiences families/caregivers carry or an absence of tools to codify and sense make around them. The last point is more profound when factoring in the current systemic practice of relying heavily on evidence-based approaches that focus primarily on behavioural impacts for the client, but are not adequately informed by lived experience of family and caregivers. The unintended impact of this current reliance on evidence-based approaches is the creation and entrenchment of system traps and design gaps that both compound and fortify challenges within systems. There are a multitude of qualitative studies that provide rich and compelling examples of the system challenges accounting for and designing around family lived experience. For example the CASDA, (2014) state

> It was clear from the feedback that they [Parents] felt that most of the ASD services were not designed for them, leaving them poorly served in the ASD sector in particular and more generally in other support sectors, such as the mental health or health sector (p.35)

The CASDA also states, a recurrent theme throughout all comments sections for Caregivers was the need for family assistance, especially with respect to system navigation. To further this theme, The Select Services Committee (2014) makes the point that there seems to be an over-assumption that every parent/caregiver is ready to be a case manager, when in fact this can be far from the truth. Further review of the ministry produced literature appears to reveal additional assumptions that coalesce around the following themes:

Caring for a child with ASD is a universally difficult experience

- “Suspecting or learning that your child has ASD or another developmental disability can be difficult, unsettling and sad experience” (Ministry of Children and Youth Services, 2013, p.8)
- “No parent can ever be prepared for a diagnosis of ASD. The diagnosis is often associated with aspects of grieving, shock, sadness or grief, anger, denial, and loneliness” (Ministry of Children and Youth Services, 2013, p.11)

Parents will be open to speak about their experience(s)

- Finally, you can also speak with other parents of children with ASD to help make sure you don't miss anything (Ministry of Children and Youth Services, 2013. p.7)

- “The transition to school can provide an opportunity for you to have an early conversation with your child’s coping and stress reducing techniques” (Ministry of Children and Youth Services, 2013, p.39)

Parents/Caregivers have a family doctor for their child

- “It is best to make an appointment with your child’s doctor as soon as possible.” Ministry of Children and Youth services, 2013, p.10)

  This assumption can increase current access gaps that are in the system for immigrant families. This idea was explored by King et al. (2011). when they noted,

  > One of the major barriers for immigrant families is lack of knowledge about how to seek health care. Families may lack knowledge of primary care of not knowing that the family doctor is important in providing entry into the system. Finding a family doctor, the entryway into the Canadian healthcare system, can be difficult for families and may lead to a delay in getting treatment for their child.” (p.20).

Power/Distance dynamic is a non-issue

The literature reviewed also did not present awareness for the potential issue of a power/distance dynamic for some parent(s)/caregivers.

- According to the Ministry of Children and Youth Services (2013) *The Autism Resources Kit*, before starting with a new therapy many parents want to ask the provider to fully understand the therapy (p.14)
- Because of the key role played by your child's principal, many parents recommend getting to know the principal and becoming comfortable with contacting them when you have questions or concerns regarding your child's educational progress or overall school experience. Developing a good relationship with your child's family physician, paediatrician or primary care physician and equally important, their administrative assistant or receptionist is important. You may want to turn to these professionals frequently for support of all kinds as your child grows (Ministry of Children and Youth Services, 2013, p.89).

Describing the experience of two-parent households is sufficient

- Even though there was some reference in the literature reviewed acknowledging different family compositions, my analysis concluded that there appears to be an assumption that the majority of households with a family member with ASD typically include two parents. This is best evidenced in the following quote. "In addition to the challenges already discussed, parents of children with ASD must navigate other aspects of family life, building a career, and maintaining healthy relationships with their partners" (Ministry of Children and Youth Services, 2013, p.92). As a

> result of this possible assumption there seems to be a gap in acknowledging that lone parents, siblings, grandparents or others also support an individual with ASD. Broadening the definition and understanding of who caregivers are is important due to the current signals and trends identified in the 2011 Canadian Census that show an evolution of both families and their living arrangements. The evolution of defining the term caregiver in Canada is best exemplified in the 2011 Canadian census that highlighted the fact that lone parent families increased 8.0% over a five year period (Statistics Canada, 2011).

The literature reviewed also mentions grandparents and siblings as individuals requiring a deeper understanding of what ASD means instead of a possible caregiver whose experiences could matter in the design of programs.

> “The library is a wonderful resource for various topics… simple books to help children/siblings understand ASD and books for grandparents” (Ministry of Children and Youth Services, 2013, p.96).

This statement can be juxtaposed with a 2009 survey by the Interactive Autism Network (IAN) of 2,600 grandparents of individuals with autism which found,

> 72% said they play some role in making treatment decisions for their grandchild. Over 34% of the respondents said they take care of their grandchild at least once a week and about one in five grandparents indicated that they provide regular transportation for the child (Anderson, 2010).

The significance of highlighting these potential assumptions is that a narrowed perspective on family/caregiver experiences may be part of the current design process. Thus creating additional barriers for a wide range of families and potentially becoming an insidious culprit for additional system wide challenges. In summary, the literature reviewed seemed to present evidence of an archetypal parent/caregiver experience that guides the selection of research methods. The viewpoints that are represented seem to lack the diversity trends that are occurring currently in Ontario. Further to this, a majority of literature reviewed did not reveal the extent of their sources, which could potentially further shape biases and assumptions and exclude the lived experience of many family/caregivers. This would especially be true if policy makers and community providers entrusted with program design are not aware of these limitations for any research they are completing and rely on evidence based research methods that have inherent barriers for some families and caregivers. This evokes two very important questions.

1. What does the literature say about the importance of family/caregiver experience in the design process?
2. If parent /caregiver voices are an important design tool how are they utilized today?

THE IMPORTANCE OF FAMILY EXPERIENCES IN THE DESIGN PROCESS

Family/caregiver engagement is critical to the design process of human services. The literature reviewed emboldens this argument. Sue Steib author of *Engaging Families in Child Welfare Practice* provides an excellent foundational definition. According to Steib (2004)

> Involvement of families is important, but real engagement goes beyond that. Families can be involved and compliant without being engaged. Engagement is about motivating and empowering families to recognize their own needs, strengths, and resources and to take an active role in changing things for the better. Engagement is what keeps families working in the long and sometimes slow process of positive change. (p,7).

The literature review also revealed principles and values toward enabling family/caregiver engaged practices and processes. Dostaler and Cannon (2011) further this idea as they state, [Engagement Is] “A philosophy and evidence-informed approach to practice focused on meeting the needs of both client and families where the family is seen as a primary component and unit of attention (P.8).” They also define family engagement as a

> process that emphasizes partnership and action. [Family engagement is] a more active partnership between families and service providers. For service providers, this means listening to what families think, engaging them in two-way communication and involving them as

> essential allies in decision making. Effective family engagement requires service providers to develop a relationship-building process focused on listening. (p. 8)

MHCC also provided recommend guidelines (MacCourt et al. 2013) for the inclusion of family/caregiver experiences and system level principles and values. Most poignant were the following recommendations:

Family caregiver inclusion and voice:

Family caregivers, advocates and organizations providing services to family caregivers are engaged in developing, reviewing and evaluating policies and programs that affect family caregivers directly or indirectly (Summerville & Atherley, 2012).

Collaboration

Promoting and supporting the health and well-being of family caregivers requires the involvement of multiple stakeholders (private sector, community based agencies, government, etc.) and ensures that relevant organizations, advocates, levels of government and individuals concerned with family caregivers are involved in developing and reviewing policies and programs.

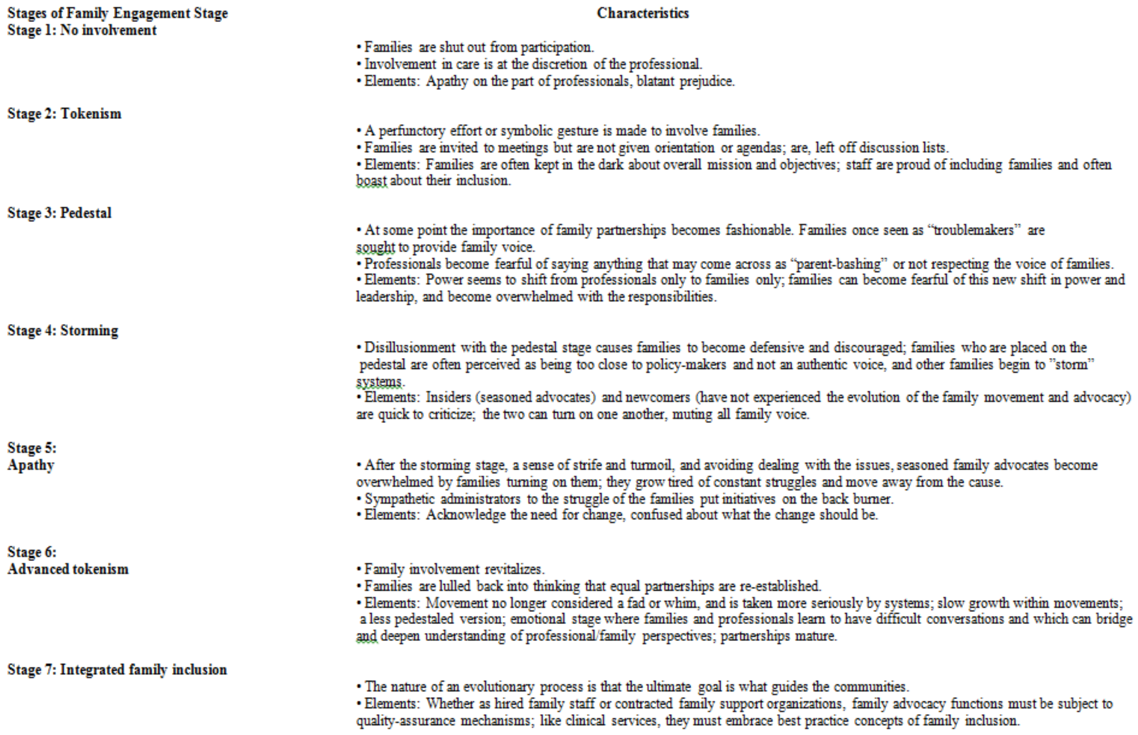
To add further clarity Dobie and Swanke (2010) identified the following characteristics of family centred philosophy and practices.

They state that responsive systems and services:

- Are concerned with both process and outcomes for clients and families
- Use strengths-based thinking to access and mobilize families
- Focus on family identified rather than processional-determined issues and solutions
- Promote the acquisition of new skills and competencies by all stakeholders
- Emphasize supports and networks

Family engagement can also be viewed as a continuum from least involved to most involved, or co-development or collaboration. Huffine and Anderson (as cited in CAMH, (2015). created the following guide that outlines their proposed developmental stages of family advocacy. This is an important inclusion to this project as it could provide a potential guidepost for the design of human services systems to account for how they measure and assess the policies and practice that encourage family/caregiver engagement and advocacy. It can also be seen as a vehicle to assess organizational or system health by way of providing an instrument of self-assessment to gauge where they are on the spectrum of effectiveness.

Figure 2: Stages of Family Engagement



Stages of Family Engagement Stage	Characteristics
Stage 1: No involvement	• Families are shut out from participation. • Involvement in care is at the discretion of the professional. • Elements: Apathy on the part of professionals, blatant prejudice.
Stage 2: Tokenism	• A perfunctory effort or symbolic gesture is made to involve families. • Families are invited to meetings but are not given orientation or agendas; are, left off discussion lists. • Elements: Families are often kept in the dark about overall mission and objectives; staff are proud of including families and often boast about their inclusion.
Stage 3: Pedestal	• At some point the importance of family partnerships becomes fashionable. Families once seen as “troublemakers” are sought to provide family voice. • Professionals become fearful of saying anything that may come across as “parent-bashing” or not respecting the voice of families. • Elements: Power seems to shift from professionals only to families only; families can become fearful of this new shift in power and leadership, and become overwhelmed with the responsibilities.
Stage 4: Storming	• Disillusionment with the pedestal stage causes families to become defensive and discouraged; families who are placed on the pedestal are often perceived as being too close to policy-makers and not an authentic voice, and other families begin to ”storm” systems. • Elements: Insiders (seasoned advocates) and newcomers (have not experienced the evolution of the family movement and advocacy) are quick to criticize; the two can turn on one another, muting all family voice.
Stage 5: Apathy	• After the storming stage, a sense of strife and turmoil, and avoiding dealing with the issues, seasoned family advocates become overwhelmed by families turning on them; they grow tired of constant struggles and move away from the cause. • Sympathetic administrators to the struggle of the families put initiatives on the back burner. • Elements: Acknowledge the need for change, confused about what the change should be.
Stage 6: Advanced tokenism	• Family involvement revitalizes. • Families are lulled back into thinking that equal partnerships are re-established. • Elements: Movement no longer considered a fad or whim, and is taken more seriously by systems; slow growth within movements; a less pedestaled version; emotional stage where families and professionals learn to have difficult conversations and which can bridge and deepen understanding of professional/family perspectives; partnerships mature.
Stage 7: Integrated family inclusion	• The nature of an evolutionary process is that the ultimate goal is what guides the communities. • Elements: Whether as hired family staff or contracted family support organizations, family advocacy functions must be subject to quality-assurance mechanisms; like clinical services, they must embrace best practice concepts of family inclusion.

Source: Stages of Family Engagement (Huffine and Anderson, 2003 as Cited in CAMH, 2015)

Huffine and Anderson’s Stages of *Family Engagement* is an important inclusion to this project as it could provide a potential guidepost for the design of human services systems to account for how they measure and assess the policies and practice that encourage family/caregiver engagement and advocacy. It can also be seen as a vehicle to assess organizational or system health by way of providing an instrument of self-assessment to gauge where they are on the spectrum of effectiveness.

Huffine and Anderson’s Stages also provides evidence that there are models of engagement practices that exist in the social services system. However, in his assessment of the current state of family engagement Rolland (2015) as cited in CAMH (2015) provides the best summary that underscores the fact that an experience gap between family/caregiver and the system at large can manifest despite these tools and models. He states, “family systems–oriented care and actual inclusion of families in a collaborative and engaging process is still uncommon, particularly at a system level.” However, even with these models and promises, there is evidence that suggests the lived experience of family/caregivers provide is still not fully integrated systemically as a design and delivery asset. Davidson et al. (2010) provide an effective summary of the value that families and caregivers contribution can contribute to strong systems of care and the fact that is still an untapped resource:

> Families are uniquely positioned to contribute to increasing the capacity of the mental health system or care through collaboration with service providers, policy makers and other families based on their personal experiences and their motivation to improve outcomes for their own children and youth. Most professionals working in the formal system of care have yet to fully recognize the benefits of actively engaging families as a way of developing system capacity and improving the quality of care (p. 169).

Therefore, this project propounds that being able to understand a range of experiences that parent(s) and caregivers possess both at a system and service delivery level is crucial to the success of both program design and delivery of services. Additional literature exists that supports this thesis. Huffine and Anderson (as cited in CAMH, (2015) state that

> It must be accepted that the process of giving voice to families can be intense, and threatening to many, and may involve hurt and danger and be very messy. But it is essential. It will take courage and a willingness to rise above personal concerns to understand the perspective of others.

In addition, Davidson et al. (2010) and Huffine and Anderson (as cited in CAMH, (2015) also state that families have critical roles in all areas of mental health systems, including program design, quality assurance and program evaluation. Cournous and Goldfinger (2014, as cited in CAMH, 2015) add to this by stating that whether at a point of care/micro, meso or marco level, families' lived experience complements and contextualizes. Additionally family/caregivers can be utilized as a recurring resource for better service design. The idea of this is illustrated well when McCammon et al. (2001 as cited in CAMH, 2015) state that family members as educators and consultants can provide unique experiences and perspectives. They have experience accessing services and supports that can provide the basis of curricula. It must also be underscored the benefits of how being engaged and having their lived experience(s) positively impact service design can have on families/caregivers themselves, including the notion of empowerment. McCammon et al. (2001 as cited in CAMH, 2015) discusses family empowerment through multiple roles in human services systems. In their assessment families/caregivers can play multiple roles including:

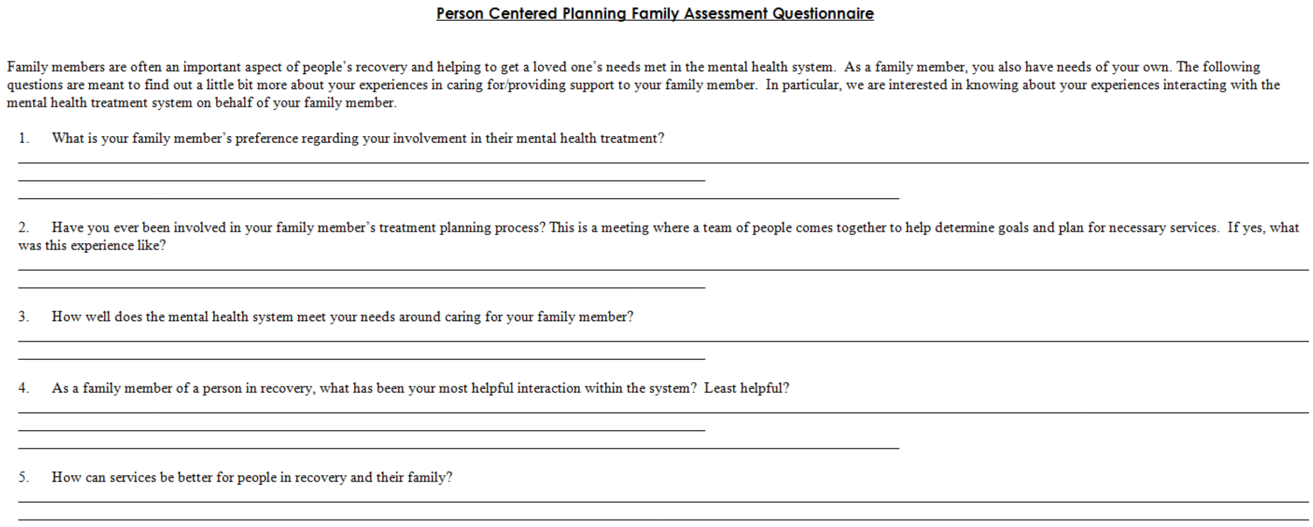
- Providers of context through lived experience
- Agents for change and recipients of service
- partners in the treatment process
- support providers
- educators and trainers of professionals, students, and other family members
- advocates
- evaluators and policy makers.

This analysis proves the value in family/caregiver engagement can be a mutually beneficial to both the system and the individuals who use it.

THE CURRENT CONTEXT OF ACQUIRING LIVED EXPERIENCE IN THE ASD SYSTEM IN ONTARIO

In pursuit of innovation it can be very common to assign a solution to a problem that doesn't exist. To avoid this project from falling prey to this fate, the following section will present a non-exhaustive review of the current qualitative research methodologies used to acquire and analyze “lived experience” in Ontario’s Autism Services System. As of 2016, the inputs that inform the ways in which human services systems in Ontario like ASD are designed and developed include: surveys, expert interviews, focus groups, and post program questionnaires. A review of post service experience questionnaire/surveys was conducted to investigate how the espoused goals about the needs of families and caregivers from organizations fits with the actual organizational processes for capturing caregiver/family lived experience. In addition, further attention was focused on what instruments are generally used to capture this type of input. Examples of findings include the following form entitled *Person Centred Planning Family Assessment Questionnaire.* This document showcases a goal of *“learning about caregiver interactions with the mental health treatment system on behalf of a family member*”. However, the format presented appears to provide limited opportunities for an individual filling it in to provide fulsome responses without space constraints. Additionally, there are three questions (2, 3, and 4) aimed at gathering information specific to the caregiver experience whereas the remaining 29 questions out of a total 32 are used to extract information about further understanding the client experience. Thus, seemingly placing emphasis on the family member/caregiver in the role of an administrative tool to gather information for client focused design. Further to this, Questions 6 - 32 appear to focus on lessening administrative constraints for whoever is inputting the information within an organization as opposed to the espoused goal of attempting to capture lived experience.

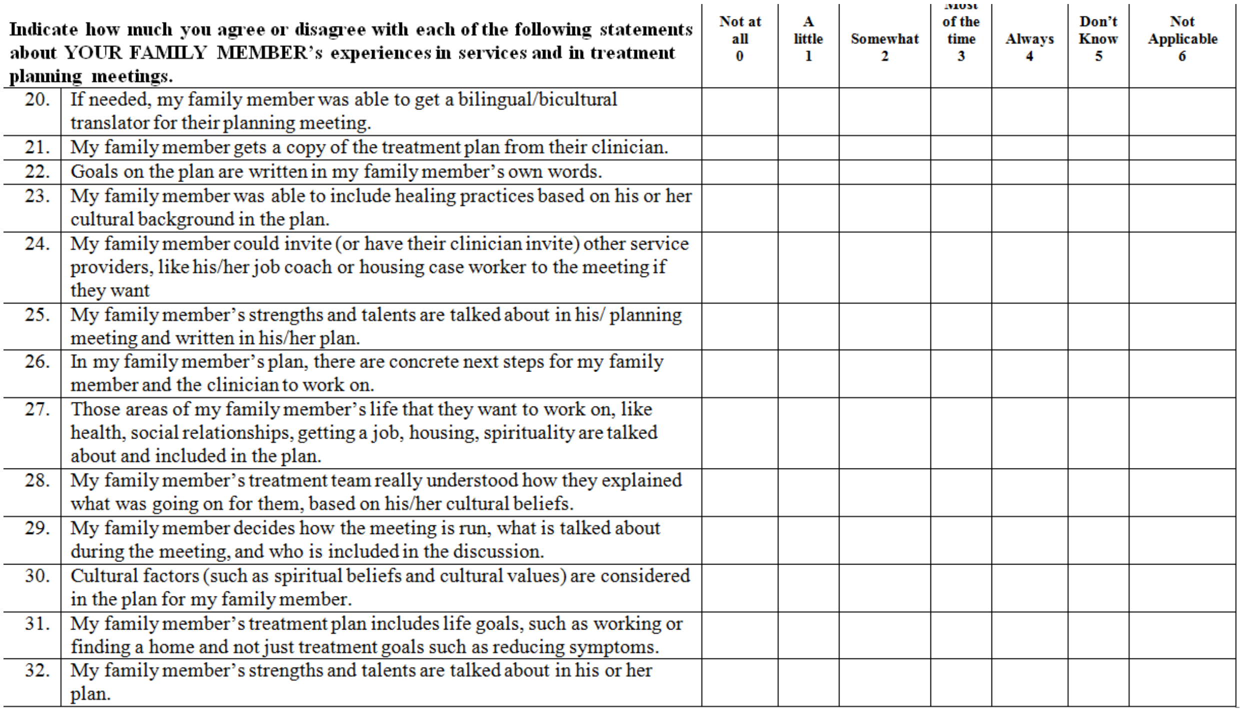
Figure 3: Person Centered Planning Family Assessment Questionnaire



Person Centered Planning Family Assessment Questionnaire

Family members are often an important aspect of people's recovery and helping to get a loved one's needs met in the mental health system. As a family member, you also have needs of your own. The following questions are meant to find out a little bit more about your experiences in caring for/providing support to your family member. In particular, we are interested in knowing about your experiences interacting with the mental health treatment system on behalf of your family member.

1. What is your family member's preference regarding your involvement in their mental health treatment?
2. Have you ever been involved in your family member's treatment planning process? This is a meeting where a team of people comes together to help determine goals and plan for necessary services. If yes, what was this experience like?
3. How well does the mental health system meet your needs around caring for your family member?
4. As a family member of a person in recovery, what has been your most helpful interaction within the system? Least helpful?
5. How can services be better for people in recovery and their family?



Indicate how much you agree or disagree with each of the following statements about YOUR FAMILY MEMBER's experiences in services and in treatment planning meetings.		**Not at all 0**	**A little 1**	**Somewhat 2**	**Most of the time 3**	**Always 4**	**Don't Know 5**	**Not Applicable 6**
20.	If needed, my family member was able to get a bilingual/bicultural translator for their planning meeting.							
21.	My family member gets a copy of the treatment plan from their clinician.							
22.	Goals on the plan are written in my family member's own words.							
23.	My family member was able to include healing practices based on his or her cultural background in the plan.							
24.	My family member could invite (or have their clinician invite) other service providers, like his/her job coach or housing case worker to the meeting if they want							
25.	My family member's strengths and talents are talked about in his/ planning meeting and written in his/her plan.							
26.	In my family member's plan, there are concrete next steps for my family member and the clinician to work on.							
27.	Those areas of my family member's life that they want to work on, like health, social relationships, getting a job, housing, spirituality are talked about and included in the plan.							
28.	My family member's treatment team really understood how they explained what was going on for them, based on his/her cultural beliefs.							
29.	My family member decides how the meeting is run, what is talked about during the meeting, and who is included in the discussion.							
30.	Cultural factors (such as spiritual beliefs and cultural values) are considered in the plan for my family member.							
31.	My family member's treatment plan includes life goals, such as working or finding a home and not just treatment goals such as reducing symptoms.							
32.	My family member's strengths and talents are talked about in his or her plan.							

Source: Person Centred Planning Family Assessment Questionnaire

The literature also revealed that disclaimers to help a reader understand the source of parent/caregivers providing perspectives is rare. For example, the viewpoints represented and selection criteria for inclusion in the Autism Parent Toolkit (Ontario, 2013) were shaped by focus groups that took place in seven locations across Ontario. Unfortunately though, there was no evidence uncovered that explained how participants were invited and how the ministry ensured diverse perspectives were represented. Additional research discovered that Autism Ontario (a member driven volunteer network of Chapters throughout Ontario that provide information, referral, and advocacy for the autism community) managed the process of obtaining participants on behalf of the ministry and did so by engaging their community through online outreach. This demonstrates a potential gap in acquiring a range of family /caregiver experiences due to the potential unintended exclusion of families based on access barriers. This adds to the evidence that there is a potential gap with acquiring knowledge of family/caregiver lived experiences especially diverse ones. In summary, analysis of the literature reviewed reveals attempts to frame the narrative of parent/caregiver experiences through limited research methods that target individuals who are most engaged while potentially missing the realities of those who would be most vulnerable. As a result, this seemingly has created a gulf in the system that unintentionally has a dominant parent/caregiver experience speaking for all. It appears this is done due to the context of the system's biggest priority which is addressing service wait times for children. Further to this, it is quite common for systems to adopt a hybrid of qualitative methods. In addition to expert interviews and focus groups, the Measure of Process of Care (MPOC-20) developed by CANCHILD (a McMaster University research centre) was contracted in 2015 by the Ontario Ministry of Children and Youth Services to conduct an evaluation of the (ABA)-based Services and Supports program across Ontario. According to CANCHILD the goal of the MPOC-20 is to evaluate the extent to which parents perceive the services that they are receiving as family-centred. CANCHILD further espouses that the MPOC-20 provides data about the characteristics and perceptions of the care that the children and families within an organization receive. Part of the promised mandate of the MPOC-20 is to also include the perspectives of parents to ensure that services measured are responsive to families' needs. The dominant research method selected to fulfill the promise of MPOC-20 is a comprehensive survey. According to CANCHILD (2015), they received responses from 55% (3450 out of

6299) of families across Ontario who were invited to participate in the first year of data collection from June 1 2015-April 15 2016. The significance of this is powerful and cannot be understated .Once again, literature reviewed does not seem to exist that indicates how diversity of lived experiences was a focus when inviting families/caregivers for a study. Equally as revealing and building upon previous signals is that there also seems to be a lack of literature to detail how efforts were made to ensure dominant group(s) would not over represent the perspectives and feedback obtained. This evidence seems to point to the fact that quantitative instruments are preferred over qualitative approaches when seeking evidence based data. This seemingly is at the expense of human stories and insights drawn from them being crunched down into quantitative data. It appears that human services systems seem to have a cultural preference for taking qualitative methods and seeing it through the prism of quantitative metrics. This is evidenced by CanChild stating “The response rate of 55% is very good for surveys of this type!” But what about the 45%? How are their voices heard? The inherent risk in acquiring lived experience only as quantitative metric is that can create a detachment in those entrusted with synthesizing and sense making from it. An example of this in the literature is JE Beatson’s 2008 article entitled Walk a Mile in Their Shoes: Implementing Family-Centred Care. In it Beatson (as cited in CAMH, 2015) states

> The decision and policy makers who inevitably work within economically restricted mandates and environments may be disconnected from practice “on the ground”. Even when models of care are evidence-based, policy needs to be attentive to potential negative consequences of

> changing models of practice, and ensure that the appropriate funding mechanisms and supports are in place preventatively, rather than reactively or not at all (p.28).

Family engagement is the first step in acquiring and utilizing the narrative power of family/caregiver lived experience(s) as a tool to help produce enhanced service design and delivery in human services systems. However, espousing the importance of such, then falling prey to organizational recursion or bureaucratic malaise can be further destructive to these systems. Further to this, my analysis concludes that within human services systems in Ontario (such as ASD) quantitative research methodologies that gauge the efficacy of programs are preferred over qualitative explorations of lived experience. It must be highlighted that despite this norm, there is a growing chorus of literature that highlights the importance of qualitative research despite its disadvantages. For example, in Cridland, Jones et al's. (2015) paper entitled *Qualitative research with families living with autism spectrum disorder): Recommendations for conducting semi structured interviews*, they state that

> Conducting qualitative research with individuals with ASD and their families is not easy. However, with these challenges also comes a multitude of rewards; predominantly, the opportunity to meet a range of different people and hear their stories (p.89).

In reference to the positive outcomes for families/caregivers living with ASD being involved in qualitative research they also point out that

> The positive outcomes of being involved in qualitative research for families living with ASD may include having an opportunity to discuss

> issues important to them, developing greater awareness and understanding of family members' perspectives, and having an opportunity to "give back" to the ASD community (p.83).

Unfortunately though, widespread adoption of qualitative family engagement practices including lived experience across systems seems to be moving at a glacial pace. There are examples in the literature that point to unintended adverse effects if system actors do not take the necessary steps to properly embed lived experience in process and service design. This is best evidenced when Clarke and Windsor, (as cited in CAMH, 2015) state that

> When organizations respond with efforts to engage families, however, often what service providers perceive as meaningful, or helpful and engaging, may be perceived by families as unhelpful, or disengaging.

There is also literature that indicates a gap still persists in terms of recognizing the benefits of engaging in this way. Davidson et al. (2010) suggest that,

> Families are uniquely positioned to contribute to increasing the capacity of the mental health system or care through collaboration with service providers, policy makers and other families based on their personal experiences and their motivation to improve outcomes for their children and youth. Most professionals working in formal systems of care have yet to fully recognize the benefits of actively engaging families as a way of developing system capacity and improving quality of care (p.169).

Instead of the status quo that exists within these systems there must be courageous and novel efforts to modernize and build the capacity required to acquire and sustain the organizational capabilities required to produce strong systems of care. MaCourt et al. (as cited in CAMH, 2015) point out that “for family engagement to be effective, creativity and flexibility in processes and structures are required because what works in one context may not work in another.” But how?

PROBLEM FRAMING: SELF REFERENTIAL DESIGN

Further reflection on my research investigations and my previously completed visual mapping exercise has resulted in some powerful signals. Although there is a great deal of literature focusing on the challenges within the Autism Services sector, there appears to be very little material that describes the practice of designing services and programs and how they account for parent/caregiver lived experiences. This led me to think about the unmistakable parallels with the classic design thinking /human factors theory of designing from an engineering perspective versus a human centered one. This thesis is put forth by Alan Cooper, author of *The Inmates Are Running the Asylum*. Cooper (1998) asserts that,

> Instead of planning and executing human-centered design strategies that satisfy the needs of the people who purchase and use their products, designers often create technologically-focused solutions that are difficult to use and control.

Once I saw the thematic parallels between engineering and policy design/service delivery and the possible assumptions within the Ontario's ASD system, I was able to assemble a list of citations/sources and conduct analysis to determine if these themes were strong or not. The results were powerful because actors in these systems entrusted with designing policy/programs and services can easily fall into the trap of designing for their own mental models. To use Cooper's (1998) own words he perfectly defines this issue, as "self-referential design". Most poignantly, Cooper continues by pointing out that unconsciously designing for oneself can generate products and services that are ineffective, unresponsive and inefficient. In addition Self-Referential Design can also create numerous process inefficiencies like:

- Difficulty determining what a product should do and how it should behave
- Lack of communication between stakeholders, developers and designers
- Failure to build consensus and commitment to a common design
- Difficulty measuring a design's effectiveness

To validate my assumption that self-referential design could indeed be a system challenge within Ontario's Autism Services System I compared results of the previous stated Ombudsman report to analyze any thematic similarities. The results are as follows:

Table 1: Self-referential design and Ombudsman Finding Analysis

Self-Referential Design Inefficiency Concept	**Ombudsman Finding**
Difficulty determining what a product should do and how it should behave	"The agencies involved said it was a challenge to find the appropriate mix of spots for each service delivery option because of the pressure to alter their clinical capacity to meet ever-changing demand" (The Office of the Auditor General of Ontario,2013, p.62).
Lack of communication between stakeholders, developers and designers	"Ontario does not have a provincial autism strategy. Canada does not have a national autism strategy" (The Office of the Auditor General of Ontario, 2013, p.57).
Failure to build	"The ministry needs to re-evaluate its program

consensus and commitment to a common design	design in order to maximize outcomes for all children served" (The Office of the Auditor General of Ontario, 2013, p.55).
Difficulty measuring a design's effectiveness	"We also noted that the ministry did not collect information that would help it monitor compliance with program guidelines and evaluate program effectiveness" (The Office of the Auditor General of Ontario, 2013, p.55).

Source: This Author

This analysis proves that individuals within the system who work on behalf of families and caregivers may be blinded by assumptions and create programs and services that are reflective of their own experiences or implicit biases. Another design problem that seems to present connections with the way services are designed is what Cooper (1998) called the "elastic user". This phrase is used to articulate the reality that can occur

> When every person on a design team has their own vision of who the end user is and what that user needs. The result is a collective "user" that becomes elastic, conveniently bending and stretching to fit the opinions and presuppositions of individual team members.

Therefore, the core problem can be summarized as a possible lack of the empathic understanding toward the audience being designed for. Including a possible lack of tools or understanding to effectively utilize the qualitative research gathered to manifest their needs. Or if this research does not exist, seek new ways of gaining these perspectives including engaging families/caregivers in the design process.

THE GAP WIDENS- AN UPDATE ON ONTARIO'S AUTISM SERVICES SYSTEM IN 2016

The tension that exists between parent/caregiver lived experiences, a system wide reliance on quantitative measurements, and a politically expedient need to focus on reduction in wait times resulted in the following significant development in Ontario's ASD System. In March 2016, a new provincial program was announced with the goal of dramatically cutting wait times in half for intensive behavioural intervention (IBI) therapy for children and youth on the spectrum by 2018, and then down to six months by 2021. According to analysis by the Toronto Star (2016)

> This approach would have impacted about 900 children with autism who are age 5 and over by no longer giving them access to the treatment. Further to this, another 1,300 who would have turned age 5 during the first two years of transition to this program would have not qualified for IBI (which is the preferred therapy route). Instead, these families/caregivers would have received a one-time payment of $8,000 to pay for supports "as they transitioned off the IBI waitlist. The initial expectation from the system was that parents/caregivers would be eventually accepting of the change."

The Toronto Star (2016) also quoted Dr. Wendy Roberts (vice-chairman of the clinical expert committee) as saying, "It will be upsetting for parents who have been hoping and waiting so long. That's certainly one of the drawbacks to phasing the whole program in. (But) it will gradually get better." The response from the negatively impacted parents was swift and powerful. The ensuing months that followed brought powerful protests from parents and advocacy groups angered by the proposed changes and the impact on their lives. Impacts that included the reality that for many the $8,000 in promised funding for other supports and services does not come close to the cost of private therapy, which costs roughly $50,000 a year. Additionally, The Toronto Star (2 April 2016) also reported that news of the age cap in March came under immediate fire from many parents, therapists, teachers and advocates who mounted an unrelenting campaign to overturn the move. This sparked a vocal grassroots backlash known as #AutismDoesntEndAt5 and fierce lobbying by the advocacy group Ontario Autism Coalition (2016). The ferocious and unwavering pressure from parents/caregivers of this campaign led to unprecedented revisions of the original program including a further $200 million in funding and promised successive payments of $10,000 for each child taken off wait lists that is intended to support families/caregivers with the cost of private treatment until the new program is ready. Additionally, the revamped plan promised to provide treatment for all children who need it by 2017 instead of the original plan of 2018.

Figure 4: Summary of the New Autism Program in Ontario (MCYS, 2016)

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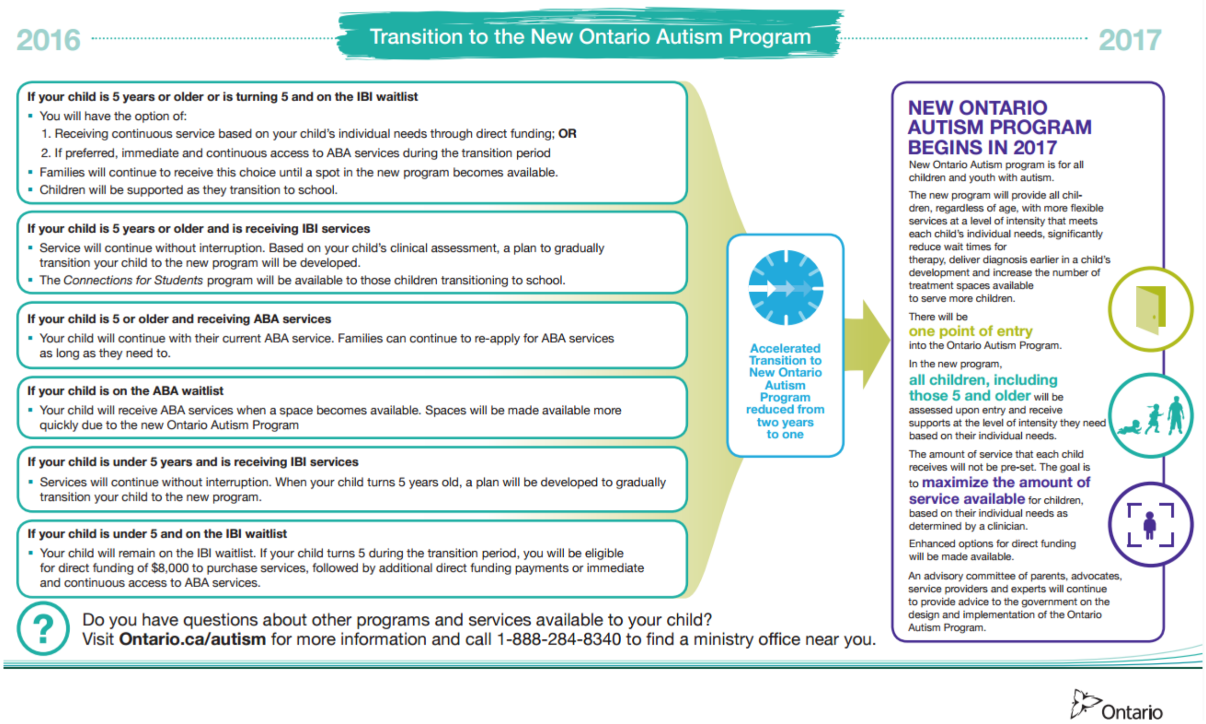


2016 Transition to the New Ontario Autism Program 2017

If your child is 5 years or older or is turning 5 and on the IBI waitlist

- You will have the option of:
  1. Receiving continuous service based on your child's individual needs through direct funding; **OR**
  2. If preferred, immediate and continuous access to ABA services during the transition period
- Families will continue to receive this choice until a spot in the new program becomes available.
- Children will be supported as they transition to school.

If your child is 5 years or older and is receiving IBI services

- Service will continue without interruption. Based on your child's clinical assessment, a plan to gradually transition your child to the new program will be developed.
- The *Connections for Students* program will be available to those children transitioning to school.

If your child is 5 or older and receiving ABA services

- Your child will continue with their current ABA service. Families can continue to re-apply for ABA services as long as they need to.

If your child is on the ABA waitlist

- Your child will receive ABA services when a space becomes available. Spaces will be made available more quickly due to the new Ontario Autism Program

If your child is under 5 years and is receiving IBI services

- Services will continue without interruption. When your child turns 5 years old, a plan will be developed to gradually transition your child to the new program.

If your child is under 5 and on the IBI waitlist

- Your child will remain on the IBI waitlist. If your child turns 5 during the transition period, you will be eligible for direct funding of $8,000 to purchase services, followed by additional direct funding payments or immediate and continuous access to ABA services.

Accelerated Transition to New Ontario Autism Program reduced from two years to one

NEW ONTARIO AUTISM PROGRAM BEGINS IN 2017

New Ontario Autism program is for all children and youth with autism.

The new program will provide all children, regardless of age, with more flexible services at a level of intensity that meets each child's individual needs, significantly reduce wait times for therapy, deliver diagnosis earlier in a child's development and increase the number of treatment spaces available to serve more children.

There will be **one point of entry** into the Ontario Autism Program.

In the new program, **all children, including those 5 and older** will be assessed upon entry and receive supports at the level of intensity they need based on their individual needs.

The amount of service that each child receives will not be pre-set. The goal is to **maximize the amount of service available** for children, based on their individual needs as determined by a clinician.

Enhanced options for direct funding will be made available.

An advisory committee of parents, advocates, service providers and experts will continue to provide advice to the government on the design and implementation of the Ontario Autism Program.

? Do you have questions about other programs and services available to your child?
Visit **Ontario.ca/autism** for more information and call 1-888-284-8340 to find a ministry office near you.

Ontario

Source:http://www.children.gov.on.ca/htdocs/English/documents/specialneeds/autism/MCYS-Autism-Roadmap-June2016_EN.pdf

The resulting response of these revisions from some parents/caregivers speaks to the heart of their lived experiences. Alison Jones of the Canadian Press quotes Kristen Ellison, a single mom to a child with ASD,

> I really wanted to hear an apology, though, she said. I really wanted them to say, 'We made a mistake. We didn't get it right. We're going to get it right now, but we're sorry that we put you through this misery (2016).

Additionally, Linda Galvao (mother of two children with ASD) was also quoted by Jones as saying,

> I just feel really upset that we even had to go through this to begin with, the amount of stress that it's put on our family, she said. I'm just saddened by the whole thing. I can't even be excited today.

The significance of this case study to this project is profound as it can be discerned that these signals once again point to either a lack of system capacity or tools to factor in the lived experiences of families/caregivers in program design. Further to this, it may provide more evidence that there may be a lack of tools to communicate lived experiences or the impacts of proposed plans on families to those who have the levers of power within a system.

This also forces the following provocative questions

To what extent was the lived experiences of parents/caregivers utilized in the decision to create the original program?

How can policy designers acquire the necessary lived experiences of families/caregivers to inform better program design, thus avoiding the missteps of 2016? What new tool(s) do policy designers and other community based partners in the system possess that demonstrate the impacts or possible futures to families/caregivers of proposed changes to those who wield influence and set policy direction? There is a growing uneasiness in the system to fundamentally change. This is powerfully illustrated when the Ministry of Children and Youth Services Michael Coteau is quoted in the Toronto Star (1 April 2016) as saying We need to hold systems accountable," he said. "When you have so many people complaining about a particular system, the status quo cannot be maintained." But how?

THE CASE FOR A NEW TYPE OF INNOVATION

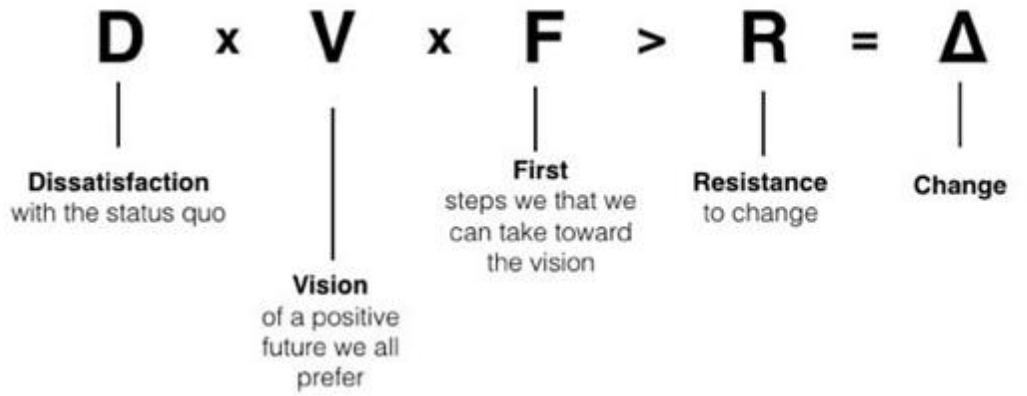
Rachel Botsman, author of *What's Mine Is Yours* and thought leader in the field of Collaborative Consumption writes about the various ways in which innovative companies have built successful business models that address underutilized assets and built trust. In her works she speaks of the sharing economy and defines it as "an economic system that unlocks the value of underused assets through platforms that match needs and haves in ways that create greater efficiency and access (Botsman, 2016)." Through my journey in this project space I could not help but think what if the central premise of Botsman's definition could also be applied within a human services system. More specifically, what if the concept of underused assets referred to the lived experience of parents/caregivers and if the terms greater efficiency and access meant providing a more evocative and effective platform for sharing lived experiences for those that are not traditionally included? Further exploration of Botsman's ideas revealed five categories she believes that if fulfilled, indicate that an industry or system is ripe for innovation. These categories are: Complex Experiences, Waste, Broken Trust, Redundant Intermediaries and Limited Access (Botsman,The Collaborative Economy 2014). The discovery of Botsman's Innovation Categories and my thoughts about the applicability of her theories to this project lead me to an exploratory phase in which I attempted to match Botsman's Innovation categories with the current state of how parent/caregiver experiences are utilized in the design Autism Services in Ontario. The results are powerful:

Table 2: Botsman Innovation Categories Compared to the Current State of How Family/Caregiver Experiences Are Included in the Design Process in Ontario's ASD System

Botsman Innovation Categories	The Current State of how Family/Caregiver experiences are included in the design of Ontario's ASD System
Complex Experiences	Parents/Caregivers of individuals with ASD face a range of personal experiences and circumstances that are as diverse and complex as the system itself. Personal circumstances will include but not be limited to cultural practices/norms, income, living arrangement, employment, location/region, household/dwelling characteristics.
Waste	Post experience surveys/questionnaires for parents/caregivers appear to focus on lessening administrative constraints for whoever is inputting the information within an organization as opposed to the espoused goal of attempting to capture lived experience.
Broken Trust	The response to the Ontario government's changes to the ASD system speaks to the heart of their lived experiences and the broken trust some feel. Alison Jones of the Canadian Press (2016) quotes Kristen Ellison, a single mom to a child with ASD."I really wanted to hear an apology, though," she said. "I really wanted them to say, 'We made a mistake. We didn't get it right. We're going to get it right now, but we're sorry that we put you through this misery.'"
Redundant Intermediaries	Continually relying on surveys as the main lived experience gathering tool and distilling the qualitative data into quantitative formats
Limited Access	Access to gaining a diversity of lived experiences has been historically limited based on barriers within racialized and diverse communities.

In addition to this, According to Dannemiller's Change Equation (Dannemiller & Jacobs,1992) (Figure 7), provide another framework to frame the next stage of exploration. According to Dannemiller in order to overcome the resistance to change (R), three elements must all be present. There must be dissatisfaction (D) of the current state, a vision (V) of what the better future state is, and an understanding of what the first steps (F) are in getting to that vision.[1]

Figure 5: Dannemiller's change equation



Source: (Dannemiller & Jacobs,1992)

I believe both Dannemiller and Botsman`s frameworks applied in the context of the ASD system in Ontario signifies there is in fact an opportunity to seek an innovative solution that modernizes how the lived experiences of Parents/Caregivers of individuals with ASD are both captured and used as a catalyst for modernizing a more responsive policy and service designs to meet the needs of parents/caregivers. But how and with what tools?

In pursuit of this answer, this project will now begin to explore the possibilities of Immersive Reality Technologies

INTRODUCTION TO IMMERSIVE REALITY TECHNOLOGIES

Immersive reality technologies will be the all-encompassing term used in this project that refers to the production of lightweight wearable head mounted displays (HMD). These displays either transport or augment a user's perception into a new type of visual and audio experience with a level of presence and immersion that traditional modes of media or computing have never been able to produce before. Although hardware is an important facet of this technology, this project will focus on the purpose and experiences generated by the technology. Understanding of this spectrum of technologies was introduced by Paul Milgram (1994) when he created the Virtuality Continuum for categorizing surroundings as perceived by the human mind. At one end of this continuum is the real environment. On the other he theorized

> The virtual environment, which refers to objects that exist in a synthetic way but not in a formal or actual state of being. In the middle of this continuum exists Augmented Reality (AR) and Mixed Reality (MR)

Figure 6: Milgram’s reality-virtuality continuum

Source: Milgram, Paul; H. Takemura; A. Utsumi; F. Kishino (1994). "Augmented Reality: A class of displays on the reality-virtuality continuum" (pdf). *Proceedings of Telemanipulator and Telepresence Technologies*. pp. 2351–34. Retrieved 2007-03-15.

The modern concept of AR can be defined as the visible natural world overlaid with a layer of digital information. Rouse et al. (2015) add to this definition by stating “AR has become a vague term for all sorts of applications that display visual information on mobile devices.” The term Mixed Reality (MR) is defined by de Souza and Sutko (2009) as the merging of real and virtual worlds to produce new environments and visualizations where physical and digital objects co-exist and interact in real time.” There are signals that point to AR and MR becoming the next modern computing platform. According to Global Market Insights (2016), The global market for AR products will surge 80 percent to $165 billion by 2024. Further to this, there are multitudes of companies and startups developing proofs of concept and prototypes of MR and AR devices that in coming years may give rise to an addressable market. As a result, this project will focus on exploring Virtual Reality technology (VR), which has a storied history of promising and producing consumer-ready technology. In its modern day incarnation, VR technology has also inspired a fervor of speculation and debate as to the type of impact it will have on the world.

HOPE OR HYPE?-THE PROMISE OF VIRTUAL REALITY

DEFINITION OF VIRTUAL REALITY

To earn the right to investigate the extent of VR as a potential source of innovation, there must first be a summary of both its definition and strenuous history. However as Woolley (1992) points out,

> Trying to trace the origins of the idea of virtual reality is like tracing the source of a river. It is produced by the accumulated flow of many streams of ideas, fed by many springs of inspiration.

Among the various definitions found in the literature, VR can be historically defined as,

> The term used to describe a three-dimensional, computer generated environment which can be explored and interacted with by a person. That person becomes part of this virtual world or is immersed within its environment. The person wears a head mounted display (HMD) or glasses which displays three-dimensional images as part of their experience
>
> (Virtual Reality Society, 2016).
>
> Some systems enable the person to experience additional input, e.g. sound or video which contributes to their overall experience. Further to this, Hilary McLellan (n.d.) adds
>
> > Virtual Reality evokes a feeling of immersion, a perceptual and psychological sense of being in the digital environment presented

> to the senses. The sense of presence or immersion is a critical feature distinguishing virtual reality from other types of computer applications (p. 461)

A BRIEF HISTORY OF VIRTUAL REALITY

Beyond its sprawling definition, the conceptual beginnings of VR as a magical portal in which a user can be transported into synthetic immersive environments has long been the subject of fascination and inspiration for 20th century science fiction writers, storytellers and technologists. In 1935 science fiction writer Stanley G. Weinbaum crafted a fictional story entitled *Pygmalion's Spectacles* (Weinbaum, 1935) which included the idea of a pair of goggles that let the wearer experience a world through holographics, touch and taste.

The historical origins of VR as a physical product began with cinematographer Morton L. Heilig. In 1955, Heilig conceived an idea to create what he called an *"Experience Theatre"* (1955) which promised to bring the feeling of realism in a simulated situation. According to the US Patent Office (1966), Heilig's original patent filing proposed an

> Invention related to an improved form of motion picture or television entertainment in which the spectator is enabled, through substantially all of his sense, to experience realistically the effect of illusion being a part of or physically responding to the environment depicted by the motion picture.

The literature also quotes Heilig as stating,

> I became very excited. I thought, "Why stop at a picture that fills only 18% of the spectator's visual field, and a two dimensional picture at that? Why

> not make it a three-dimensional image that fills 100 % of the spectator's visual field, accompanied by stereoscopic sound? If we're going to step through the window into another world, why not go the whole way? (Tate, 1996)

The end result of Heilig's Experience Theatre led way to another invention of his called the *Sensorama (Heilig, 1962).* The Sensorama was a one-person theater that included three-dimensional, full color film, sounds, smells, and the feeling of motion, as well as the sensation of wind on the viewer's face. The end result of the Sensorama was similar in that it was not a success.

Heilig's vision and Weinbaum's imagination endured for many decades becoming the precursor to various attempts at realizing the dream of Virtual Reality. These attempts included flight simulators and head mounted displays that facilitated learning for military training beginning in the 1960s and 70's. The late 1980's and early 90's also presented another arena of opportunity for VR. According to McClellan (n.d.)

> During the late 1980s and early 1990s, there was widespread popular excitement about virtual reality. But the great expense of the technology and its inability to meet people's high expectations at this early stage of development, led to a diminution of excitement and visibility that coincided with the emergence of the World Wide Web. Although the hype for this technology receded, eclipsed by enthusiasm for the World Wide Web, serious research and development continued. (p. 463)

By the late 20th century, the VR industry was teetering on the brink of becoming a perpetual disappointment based on the consistent and continual narrative befalling countless iterations of devices that fell short of expectations. These unmet expectations were once again based on low resolution displays, slow graphics and high cost. This narrative continued until the early 2000’s when the rapid rise and relentless competitive landscape of the smartphone industry changed everything. This is best evidenced in an article written by Kevin Kelly (2016) in WIRED Magazine when he states,

> Its [The Smartphone] runaway global success drove the quality of tiny hi-res screens way up and their cost way down. Gyroscopes and motion sensors embedded in phones could be borrowed by VR displays to track head, hand, and body positions for pennies. And the processing power of a modern phone’s chip was equal to an old supercomputer, streaming movies on the tiny screen with ease.

Thus, a new area was born lead by video game enthusiasts and a new wave of inventors who successfully created lightweight headsets reigniting the potential that Virtual Reality would be a viable and powerful industry. This point is underscored when Jeremy Bailenson (Director of the Virtual Human Interaction Lab) states,

> We’ve really seen a tipping point in the last year/year and half maybe two years. So for the first time ever we’ve had very large industry pouring in billions of dollars with hundreds and hundreds of engineers at a problem that was very difficult to do before. (Bailenson (2016, August 15).

The grey literature reviewed also provides multiple sources reinforcing the belief that the adoption of VR and VR content into the mainstream has finally made inroads as a viable consumer product. According to Report Buyer,

> A number of lessons have been learned since the 1990s when consumer VR last generated this much hype, with huge strides having been made on the comfort of HMDs, creating a convincing level of immersion, the emergence of standards, and the development of compelling content. Getting users to experience VR technology firsthand and therefore truly understand its potential, remains a challenge, but the emergence of low-cost mobile VR solutions is helping. (23, March 2016)

Additionally, the industry is expected to grow. According to a Superdata Research report “the VR industry will generate the global market for Virtual Reality is expected to $12.3 billion in 2018 (2017).”

CURRENT STATE OF THE VR MARKET

VR as an industry is still in its early phases and is essentially an industry of industries. Various content developers produce applications including games, movies, social and video experiences. Meanwhile a growing number of manufacturers is producing HMD’s, haptic components, and cameras for 360 degree video.

EMPATHY MACHINE OR HYPE MACHINE?

Beyond video games and movies, developing VR content and experiences has evolved from strictly being computer generated representations of real and fantasy like environments to also include panoramic video content of actual environments. The significance of 360 degree video content as a standalone VR experience is that it potentially provides an opportunity to impact human emotions by allowing one the possibility of feeling a sense of presence and immersion in realistic environments. Presence and immersion are the “x factors” that enable VR the distinction of being a potential transformative technology. The distinction is important to note between the two terms. According to Slater and Wilber (1997).

> Presence in a Virtual [Reality] Environment (VE) is inherently a function of the user’s psychology, representing the extent to which an individual experiences the virtual setting as the one in which they are consciously present. On the other hand, immersion can be regarded as a quality of the system’s technology, an objective measure of the extent to which the system presents a vivid virtual environment while shutting out physical reality

The significance of user presence through VR is that it has the potential to create experiences that can impact human emotions and empathy to a greater degree than traditional flat media can achieve. To achieve the result of creating immersive experiences there are a range of consumer VR headsets being produced that result in various degrees of user immersion and presence.

Table 3: Summary of Technology Available in 2017

Headset Type	**Description**	**Level of Immersion and Presence**
Light Mobile	The most simple and affordable of virtual reality headset options. It is made out of a pair of plastic magnifying lenses and a sheet of corrugated cardboard. A user will insert their smart phone in the self-assembled cardboard viewer. The smartphone screen will be magnified to give the user a sense of Presence. Typically using 360 degree video	low
Mid-Range Mobile	Similar to light mobile in that users require a smartphone inserted into a headset that has magnified lenses. However mid-range devices also have motion sensors that are able to track movement and thus increase the quality of the immersive experience	**Mid**
Full Immersive Tethered	Headsets in this category rely on external computers or game consoles. Because of this additional computational and graphical power they provide the highest resolution screens, graphics and motion tracking. They provide the most realistic experience and the greatest sense of presence for users	**High**

Adapted from Source: Robertson, A. (2016). THE ULTIMATE VR HEADSET BUYER'S GUIDE. Retrieved from http://www.theverge.com/a/best-vr-headset-oculus-rift-samsung-gear-htc-vive-virtual-reality

Even though this industry is still emerging, the current range of VR headsets enables a wide range of immersion and presence options. This range has resulted in numerous content creators and innovators creating VR experiences for multiple industries. A summary of the industries and sectors described in the grey literature to be potentially impacted and disrupted by VR are as follows:

Table 4: Summary of Expected Industries To Be Impacted By VR

Visualization	**Physical Experience**	**Digital Entertainment**	**Education/ Simulation**	**Ecommerce**	**Healthcare**
Art Science Architecture Real Estate	Music Sports Travel	Gaming Movies Concerts	Staff Training Military Field Trips	Shopping Virtual Commerce	Treatment Therapy

The articulation of VR as a potential transformative technology for the above stated sample industries has been expressed vividly in popular media. Below is a summary of selected quotes from literature (both peer reviewed and grey).

Selected Quotes:

- The amazement people feel when experiencing VR has spawned a new branch of philosophical and scientific inquiry into what presence is, the factors that contribute to the degree of presence in VR, and how the degree of presence affects the usefulness of VR in research, training, treatment of phobias etc. (Loomis 2016)

- For the first time in human history, people are going to be able to hit a button and have any experience they can fathom. Go to the top of Mt. Kilimanjaro, become somebody else, experience something wonderful, experience something horrible, all at the touch of a button and the brain is going to treat that as if it were a real experience. In other words, humans have been around for a very long time, we have not yet evolved (the brain hasn't) to really understand the difference between a compelling virtual reality experience and an actual one." (Bailenson (2016, August 15).
- "VR will be more than just a storytelling platform. It will be a platform for sharing our inner self—our very humanity". (Milk, 2016)

- "Virtual Reality offers a whole different medium to tell stories that really connect people and create an empathic connection. We call Virtual Reality the empathy machine"
  Nonny de le Pena CEO Emblamatic Group
  (Young, Parise, Hoffman& Killick 2016, March)

- Imagine 10 years ago trying to envision the way we use cellphones today. It's impossible. That's the promise VR has today. VR at its best shouldn't replace real life; just modify it, giving us access to so much just out of reach physically, economically. If you can dream it, VR can make it. It's a medium for progress, not itself.
  (Schnipper (n.d.)

- “Virtual reality is the ‘ultimate empathy machine.’ These experiences are more than documentaries. They’re opportunities to walk a mile in someone else’s shoes.” Chris Milk

  Fox, E. J. (2015, December)

- From real estate, to travel and gaming, we’re about to experience a digital revolution that will change the way we live, work and play, much like the internet did for us in the early 2000′s.

  Forbes Magazine

Adams, R. L. (2016, September 7)

After recognizing a consistent theme throughout the literature I was able to take a step back and critically determine the potential for bias in the citations. Despite my analysis there was still an underlying theme consistent in all the reviewed literature. The theme is that VR (even though in its technological infancy) has the potential to be a tool for change in many industries. As a result, this project's focus will sharpen around the following central premise. If VR is truly on a trajectory to be a disruptive and transformative technology as prophesied for many industries, then to what extent can it be an instrument of innovation in complex human centered systems? It is this fundamental question that provides a bridge that links back to Part 1 of this project. More specifically, how might VR be a tool in the design of human services (Including the ASD system in Ontario)? As a first step in answering this question, a cursory exploration of how VR is currently used in the provision of Autism Services was completed to provide both context and a foundation for inquiry.

> **“THE GREATER THE DISTANCE BETWEEN THE PROBLEM AND THE ANALOGOUS FIELD, THE GREATER THE NOVELTY OF THE SOLUTIONS”**
>
> (Poetz,Franke & Schreier, 2014)

VR CURRENTLY IN THE ASD SERVICES SECTOR

A cursory review of the current instances of VR in Autism Services systems has revealed evidence that demonstrates a possible preference for using the technology as an intervention and skill development tool for children and youth with a diagnosis. To support this approach, a number of researchers have made the case that VR can be beneficial in the treatment of ASD. According to Parsons and Cobb,

> VR is argued to offer particular benefits for children on the autism spectrum, chiefly because it can offer simulations of authentic real-world situations in a carefully controlled and safe environment (2011).

Evidence of the acceptance of VR used as an intervention tool in ASD systems was gathered through keyword searches using references tools to validate the discovery of this signal .Examples of the results yielded as of March 2017 are as follows:

- *Effectiveness of virtual reality for teaching street-crossing skills to children and adolescents with autism.*
  (Josman, Ben Chaim, Friedrich, Weiss, 2011)
- *Virtual reality social cognition training for young adults with high-functioning autism*
  (Kandalaft, Didehbani, Krawczyk, D.C. et al. 2013)

- *Virtual reality job interview training in adults with autism spectrum disorder* (Smith, Ginger, Wright, et al. 2014)
- *Development of symbolic play through the use of virtual reality tools in children with autistic spectrum disorders: Two case studies*
  (Herrera et al. 2008)
- *Reduced Mimicry to Virtual Reality Avatars in Autism Spectrum Disorder* (Forbes et al. 2016)

The significance of these findings is that it provides some validation of current trends that show a leaning to investigate the use of VR technology as a skill development or treatment tool for children and youth with a diagnosis. To further support this approach, Newbutt et al. add that,

> Virtual Reality (VR) provides opportunities to practice dynamic and real-life social interactions, which has been used previously and shown to be an effective intervention tool for people with autism. Testing and using VR as a possible tool of innovation for treatment is both a necessary and expected pathway to produce modern and evidence based options for service delivery (2016).

However, is there a potential for VR to not only support the delivery of ASD services but also the design of them? Based on the challenges presented in Part 1 of this paper, the fundamental question is could VR also be used as a tool for capturing and sharing the lived experience of families/caregivers?

In pursuit of answering the second question, this project will now explore signals that demonstrate a possible shift toward greater emphasis on increasing family engagement and parent voice in human services systems. Thus, possibly creating the right conditions for VR as a potential lived experience tool.

SIGNALS OF CHANGE

Complex human services systems (including the ASD system in Ontario) have long sought various levels of system change beyond treatment innovations. Recent signals show efforts to increase family wellbeing and engagement. These signals include providing families/caregivers with opportunities to be part of therapy based groups such as Cognitive Behaviour Therapy (CBT), Acceptance and Commitment Therapy (ACT) and Mindfulness. Additional signals also include seeking family members to become part of committees and working groups to provide a voice of the family: Evidence in the literature points to the effectiveness of these programs to support the wellbeing of parents/caregivers.

ACT

"Practitioners working with parents of children diagnosed with autism may see benefits from incorporating ACT strategies into their treatment planning and implementation." (Montgomery, 2015)

Mindfulness

In their study entitled: *Effectiveness of Mindfulness-Based Intervention on Perceived Stress, Anxiety, and Depression Among Parents of Children with Autism Spectrum Disorder,* Rayan and Ahmad (2016) included 104 parents of children with ASD in a study and concluded that Mindfulness Based Interventions (MBIs) are culturally adaptable, feasible, and effective interventions to improve psychological well-being in parents of children with ASD.

Figure 7: Poster for Grand Opening of the Office of Family Engagement

.ca familyengagement@camh
familyengagement@camh.ca
ment@camh.ca familyengage
engagement@camh.ca familye

Please join us for the

grand opening of the Office of Family Engagement,

home to CAMH's new Family Resource Centre, the Family Advisory Committee, and a host of exciting initiatives to strengthen the family voice at CAMH.

Thursday, March 23, 2017
2:00 to 5:00 p.m.
Room 1314
Bell Gateway Building
100 Stokes Street
(please gather in the oasis at 1301, ground floor).

Please RSVP to familyengagement@camh.ca
or **416 535-8501, ext. 33202**
We look forward to seeing you as we open the doors to the Family Centre!

camh Office of Family Engagement

Source: (CAMH, 2017)

Even though these efforts are proving to be effective as support and engagement interventions, these opportunities are not widely available to all families and caregivers. Further to this, the contextual environment of where these initiatives take place may make them susceptible to falling into the same system traps and described in Part 1 of this project or non-impactful in the way services are designed. As a result, how can families/caregivers be empowered to tell their stories directly? In other words, what if there was another tool in pursuit of engaging families/caregivers that enabled them to share their own lived experiences? What if this medium transferred a sense of visceral presence and understanding that focus groups, interviews, surveys and questionnaires that are distilled into quantitative data, could not achieve? What if policy makers and service designers had tools that attempted to enable a greater understanding of the lived experience of families/caregivers to support responsive service design and delivery? If VR is the missing quotient then all that is required is a meaningful project to test this theory. For this, I looked no further than my own experiences.

TOWARDS A NEW PHENOMENOLOGY

I am both a parent and a caregiver (sibling) to individuals with ASD. These roles have been a central part of the fabric of my life. All my ambitions, successes, failures and redemptive moments have all at one point or another been experienced through the anxiety and fear of asking, “How might this impact my ability to protect that space in my life, dedicated to supporting my family members’ diverse needs?” As honourable as this sounds, it is not easy. I am human and I have felt the strain that many parents and caregivers often feel. It can be numbing, ever stressful and wildly unpredictable. I believed I could tap into my experiences as a gateway into recording a VR experience for this project. As ambitious as this sounded, it was even more difficult to execute. I had no VR equipment, the price was high and availability of 360 cameras was scarce at best. I had no skills to record or edit VR, and no plan of action for what to record. I was dangerously close to having a solution without a problem. The ensuing months were filled with days where I struggled to think of a path forward. This left me crestfallen. I began to think that recording a VR experience for this project was too ambitious an idea. I also questioned that even if I was able create a VR experience would it be good enough let alone innovative enough? And most vividly in my mind, would any attempt at exploring a nascent technology result in the cultural and complex bureaucratic structures that exist in Human Service Systems to simply tower over and stomp on any attempt at system innovation in favour of the familiar and risk averse? These were all questions that haunted me for months. It was at this moment, I felt the shadow of Goliath lurching towards me. Until one day an opportunity arose from a soon-to-be-life-changing event for my family.

A CAREGIVER’S JOURNEY

In August of 2016, I received phone call informing me that my older brother who has a dual diagnosis including ASD had been formally invited to begin the process of being accepted to live in a group home. This opportunity represented the potential for a big shift in my family dynamics as my brother lived with my mother for 45 years. Their living situation was assisted by community housing and social assistance programs. Often times precarious, their day to day living was impacted but not defined by tense moments of crisis my brother had while my mom struggled to balance supporting his complex needs while caring for herself. I often provided caregiver support during these moments of crisis including advocacy for additional supports and accommodations. The stresses and pressures I felt as a caregiver were not as heavy as my mother faced, but I began to feel my ability to manage difficult because I have usually been the one to hold it all together. As the process continued I recognized the changes that a move for my brother would bring to his life would also potentially create additional challenges and hardships for my mother. This was due to the fact that her sense of self was tied to supporting and caring for my brother. She is his fiercest advocate and he is her best friend. I felt that any move would upend this dynamic and potentially put my mother at risk for depression. Finally, the day came in which my brother was formally offered a spot in the group home. The task list of items to be taken care of before my brother moved in included:

1. Informing and preparing my brother of the move
2. Informing the relevant social assistance agencies of the move
3. Being the conduit between the group home and my mother to confirm logistics of my brother's care and day to day living needs (including all things medical)
4. Supporting and monitoring my mother's emotional well-being during the process

Like most caregivers I put my head down and became task oriented. At a blistering pace I was able to work my way down the list to help ensure my brother's room was ready for move in. Also, like most caregivers I put my thoughts and feelings secondary to focus on supporting both he and my mother. The cycle was poised to continue with my hard- to- express feelings now suppressed in favour of the end result. My experiences with this process and thoughts I had about how things impacted me was of secondary value. My only outlet of expression was the late night reflective moments driving home. The survey I was asked to fill out asked for quantitative feedback on how effective were these services to support my brother, and not about my experiences as a caregiver. This might have been the final result, but not this time. It was at this moment I thought of the possibility of using my experiences with my brother's move as a potential prototype to test the central research question of this project. I then made the decision to move forward with the idea of recording myself using a 360-degree camera and producing a VR experience prototype. The prototype would aim to showcase the cathartic experience of a caregiver's journey.

The future is already here — it's just not very evenly distributed.

(Gibson, 1999)

RESEARCH

PURPOSE

The purpose of this research study is to explore the possibilities of using VR as a tool for capturing and viewing the lived experiences of families/caregivers in human services systems such as the ASD system in Ontario. The study will achieve its purpose by chronicling the process of a family/caregiver storyboarding prototyping, recording, editing and prototyping a VR experience during a pivotal family moment The intent of this study is also to provide a foundational and germane application of immersive reality technologies within complex human services systems. Thus, inspiring potential future applications of these technologies as a possible tool for service design. To achieve this goal, feedback from experts who currently work in the field of human services will be engaged to seek feedback on the VR prototype's applicability, possibilities and challenges as an adopted tool within the systems in which they work. Thus, gathering insights on the potential of current and future manifestations of immersive reality technologies to become a qualitative research method or education tool. A tool that could potentially support a greater understanding of family/caregiver experiences in the near future.

RESEARCH METHODS

Various research methods were applied in this research project and were separated into three phases:

1. Prototype the creation of a 360 degree video showcasing a lived experience moment
2. Autoethnographic reflections of my experiences as a caregiver in the creation of a VR prototype
3. Expert interviews with professionals in the ASD system in Ontario to obtain feedback on the prototype's potential as a lived experience tool

The following is a summary of the research methods conducted for this study including the rationale for inclusion.

Table 4: Summary of Research Methods and Rationale

Research Method	**Rationale**	**Participants**
Prototyping	Creating a prototype would be that it provides a template for future iterations, studies and or implementation.	Self
Research Method	**Rationale**	**Participants**
Autoethnography	To provide a summary of my experiences as a caregiver within the ASD system in Ontario creating a VR prototype. This would potentially enable a roadmap for future research	Self
Expert Interviews	To test the effectiveness, obtain ideas, insights and challenges of adopting VR as a lived experience tool by professionals who work in a human services system (ASD).	Professionals in the ASD service system. To ensure requisite variety, a diverse group of individuals and roles was desired.

Source: This Author

PROTOTYPE DEVELOPMENT

This section will provide a summary of my development process followed by an autoethnographic reflection of my experience making a VR prototype.

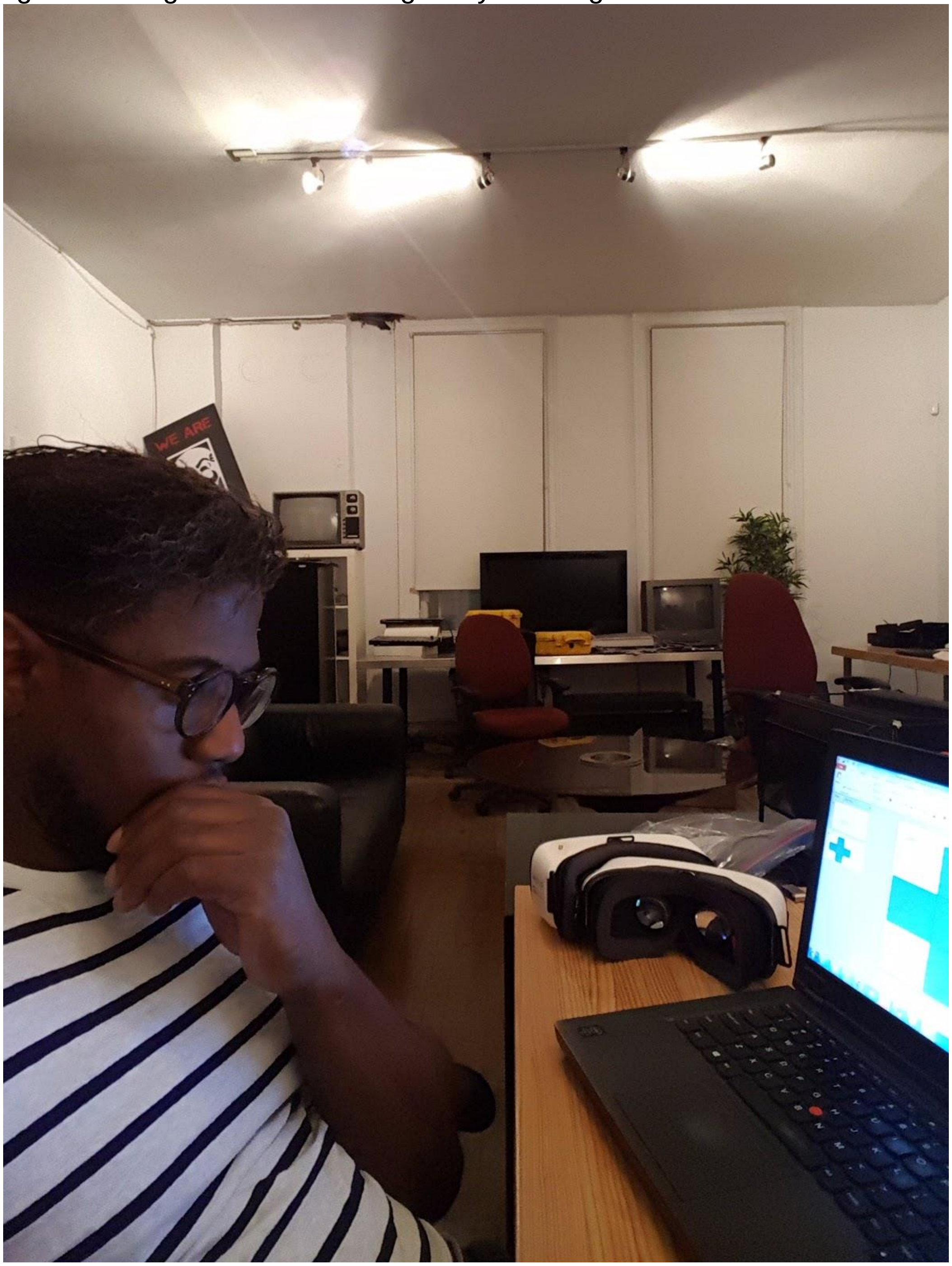
The development process for the creation of the prototype was as follows:

1. Storyboard
2. Pre-shooting test and set up
3. Shooting
4. Editing

Storyboard

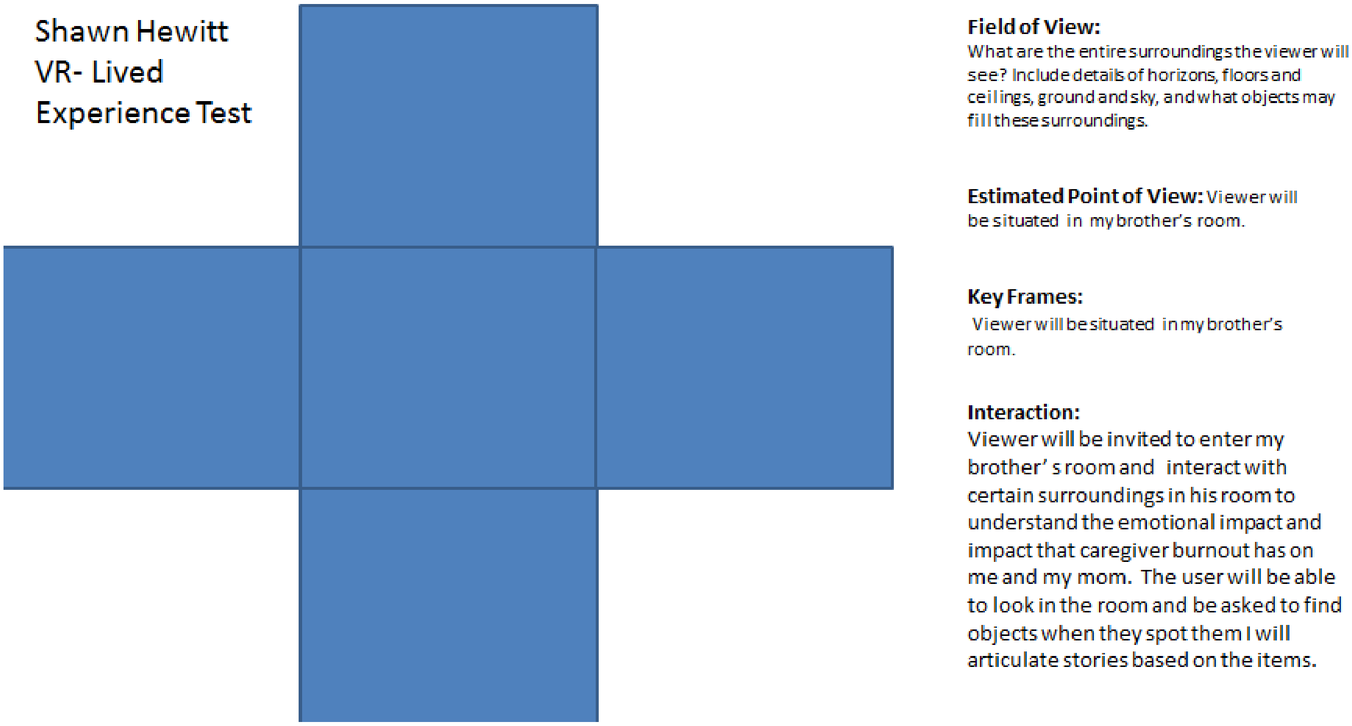
The creation of a storyboard was intended to provide a structural backbone to which the prototype would be created. Iterations of the storyboard were more aspirational as I was not aware of the technical capacity requirements to achieve an optimal VR experience. I used Microsoft PowerPoint in an attempt to articulate my ideas. During this phase of development, I was not factoring in details such as time constraints, wardrobe, time of day, lighting, etc. Consent was obtained from my brother's group home to conduct shooting in his room. However, I chose not to shoot any vulnerable persons including my brother, mother, residents in the home or staff adhering to research ethics. During shooting I chose also to exclude all personal identifiers such as family photos.

Figure 8: Image of Shawn During Storyboarding Process



Source: This Author

Figure 9: Sample Storyboard Draft



Shawn Hewitt
VR- Lived
Experience Test

Field of View:
What are the entire surroundings the viewer will see? Include details of horizons, floors and ceilings, ground and sky, and what objects may fill these surroundings.

Estimated Point of View: Viewer will be situated in my brother's room.

Key Frames:
Viewer will be situated in my brother's room.

Interaction:
Viewer will be invited to enter my brother' s room and interact with certain surroundings in his room to understand the emotional impact and impact that caregiver burnout has on me and my mom. The user will be able to look in the room and be asked to find objects when they spot them I will articulate stories based on the items.

Source: This Author

Reflection on Storyboard Process

As a creative exercise I felt storyboarding was an important starting point to plot out what the best approach was for filming. I had a difficult time coming to a decision if I should be on or off camera, with script or without a script. It was at this stage my initial fear of authenticity began. I was afraid of over-curating a moment that I wanted to be pure and powerful. I was also concerned during this phase that my experience would be very restricted based on the risk mitigation strategies I needed to execute to ensure REB approval. Upon reflection these concerns were accurate. It was at this point I decided to restrict the recording solely to myself on camera, speaking directly about my experience and giving a small tour of the room. I calculated that providing a monologue with a protagonist (myself) would be easier for study participants to follow and enable the core messaging to not be overshadowed by the “cool factor” of the technology for participants who have not experienced VR before.

Pre-Filming Test

Once I was comfortable with the direction I wanted for the prototype I was able to establish a relationship with Occupied VR (a Toronto-based Virtual Reality and Presence Studio) that allowed me to borrow (in kind) a 360 degree camera and editing space to produce my experience. During this phase I completed a number of tests to understand how the camera functioned, ensuring that there would be no technical glitches during shooting day. For this prototype I used the following equipment.

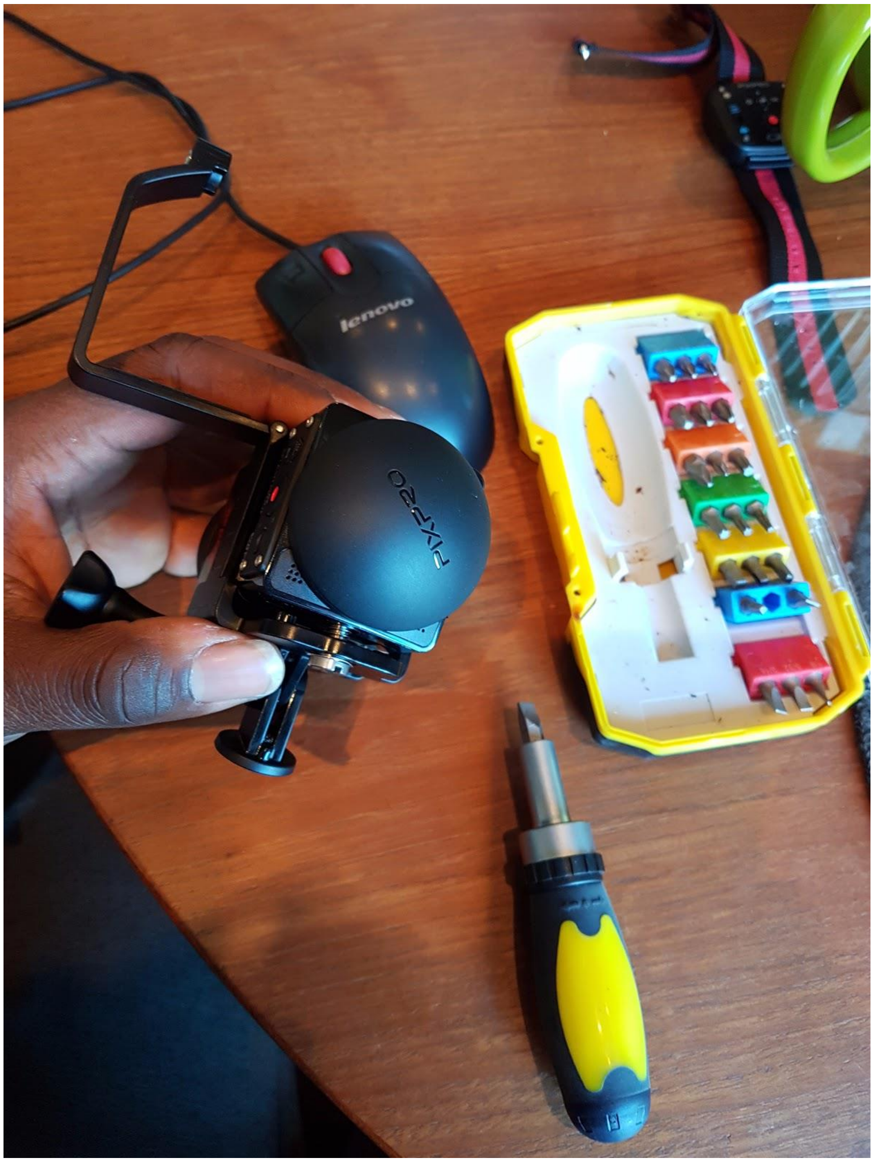
- Kodak Pixpro SP360
- Samsung Gear VR

Figure 10: Image of Equipment Used for Prototype

Source: This Author

My rationale in using the Samsung Gear VR was that I felt it would provide enough level of immersion required for the prototype and was the most economical and logistically easy option for this study and potential implementation within human services systems.

Figure 11: Image of Shawn Preparing 360 degree camera



Source: This Author

Figure 12: Image of Shawn Setting Up Camera For Test

Source: This Author

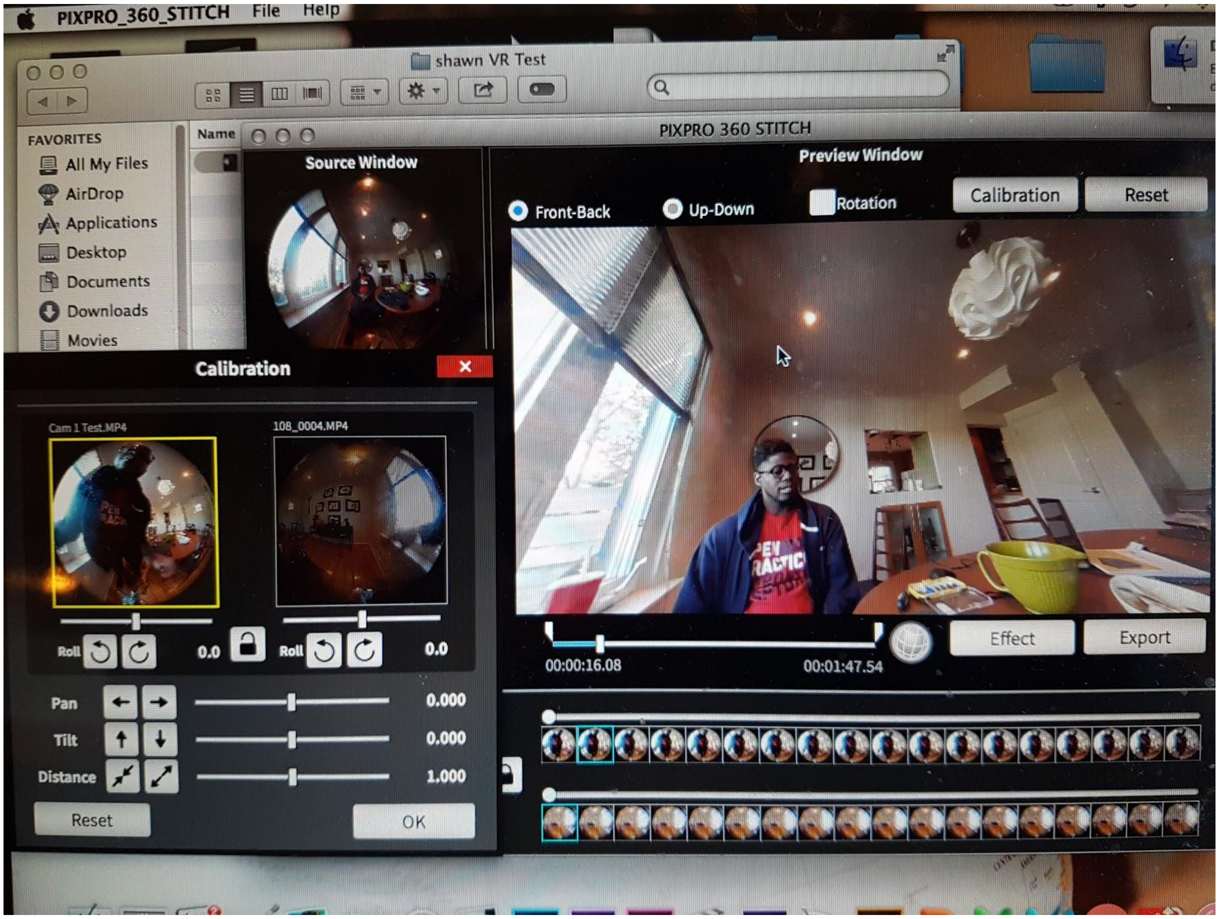
Figure 13: Image of Completed Camera Set Up

Source: This Author

Figure 14: Image of Camera Test 1

Source: This Author

Figure 15: Image of Camera Test 2



Roll 0.0
Roll 0.0
Pan 0.000
Tilt 0.000
Distance 1.000
00:00:16.08
00:01:47.54

Source: This Author

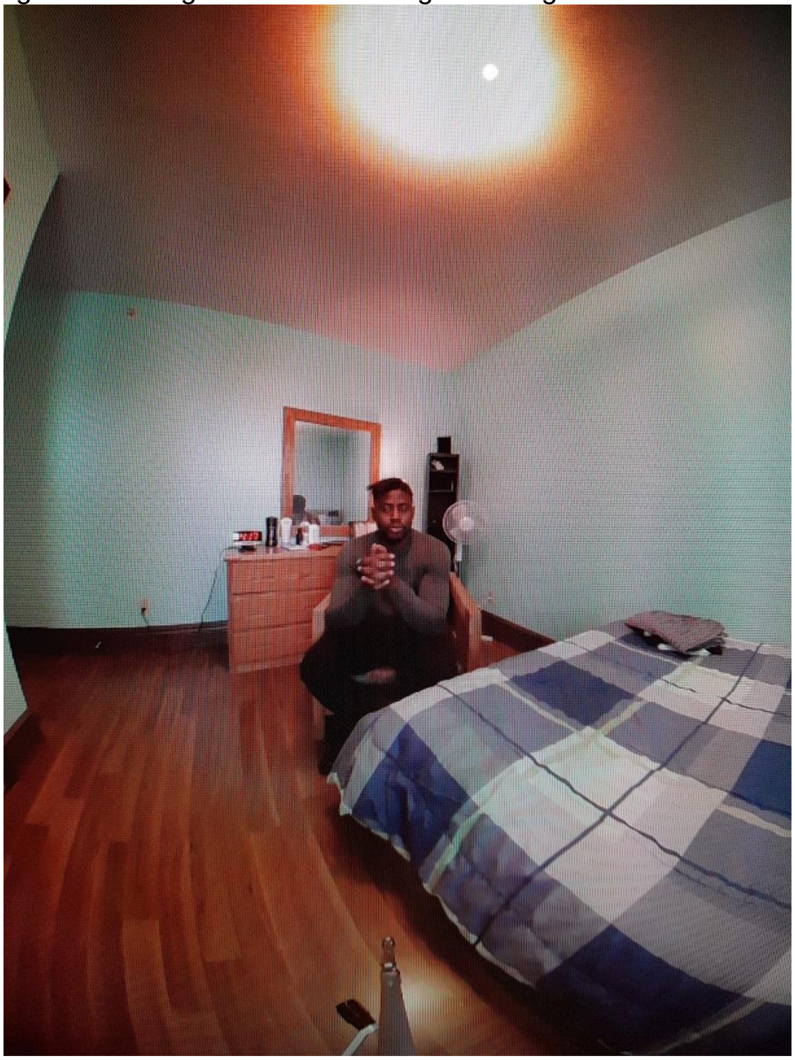
Reflection on Pre Filming Test Process

In reflection, it was not very difficult to physically set up the camera rig but it was difficult to learn that whatever I was filming I could not preview. I would need to wait until the editing phase to see if my footage was usable. This fact increased my anxiety. As a lesson learned, I would have set up a site visit beforehand and do a test in the actual space to get a feel for the environment. This is because I estimate high probability that if families/caregivers will utilize this tool they will be recording experiences in familiar environments.

Shooting Part 1: My Brother's New Room

The shooting experience went by without any major technical glitches except running out of memory in my SD cards on two occasions. In total I recorded 38 minutes worth of material.

Figure 16: Image of Shawn during Shooting



Source: This Author

Reflection on Shooting Process Part 1

At times I felt uncomfortable about the production. During filming I found myself in my own head trying to think of ways to pique the interest and emotions in viewers as opposed to focusing on my experience. I already knew I was not able to preview what I recorded. However, when I was standing in the room my level of concern rose. I also found myself over thinking about how effective the experience would be. This overthinking impacted my ability to be myself on camera. When I finally let myself forget the camera was there I was a bit more articulate and a bit more present. Thus, allowing myself to be free to express myself as openly as I could. As a lesson learned it would have been good to have key points written down to better frame my narrative.

Shooting Part 2: My Brother's Old Room

The second and final stage of filming occurred in my brother's old room. The rationale behind the decision to film at this location was to provide an update on how my feelings progressed since the first film shoot and for an attempt to implement the lessons learned from my first filming experience. All precautions were also undertaken to ensure no vulnerable persons (including my mother) and identifiers of them (like photos) were not captured.

Reflection on Shooting Process Part 2

In reflection, in this scene I was still having issues with finding the right narrative voice to use. I also continued to feel the tension of not showing enough emotions vs. over acting. Despite these valuable lessons, I still feel the recording was effective at capturing the purity of the moment including its flaws. Overall I felt very satisfied about the recording experience and felt a source of strength and confidence as a result.

Editing

During this phase I used the following software courtesy of Occupied VR:

- Adobe Premiere
- Autopano Kolor
- Autopano Giga

The editing process began with taking my raw footage and stitching it using Autopano Kolor and Autopano Giga to create 360-degree footage. Once this was completed, the stitched footage was then edited in Adobe Premiere to create a condensed 12-minute experience. Total editing time was three days.

Reflection on Editing Process

During the editing phase I felt very tense about what I would be choosing to edit and what to keep. At first I wanted to delete areas I found very jarring (for example me yelling at my mother to leave the room) in favour of footage that showed a more coherent and calmer tone I was using in the video. Then I realized that it was the raw and unvarnished/uncomfortable moments I originally wanted to edit out that I needed more of. This was based on the realization that instead of me saying I was stressed and anxious a viewer would be best served if they got a raw sense of it. Concluding the editing phase felt like a triumph nonetheless. Once I finished editing the prototype and viewed the experience for the first time using the headset I felt my sense of strength growing. I shed a tear for this achievement. Recording and editing my caregiver’s journey in VR was complete. It was now time to test its utility and get reactions from experts.

PROTOTYPE FEEDBACK: EXPERT INTERVIEWS

INTRODUCTION

Once the VR experience was completed the next phase of the study was to use the prototype as a tool to obtain feedback and insights from professionals who work in the ASD system in Ontario. The purpose of this approach was to obtain professional feedback and insights on:

- possible strengths and weakness of VR as a lived experience tool to support service design
- what current barriers exist to prevent the implementation of VR as a lived experience tool for human services systems
- additional ideas of how VR could be used to support service design in human services systems including Ontario’s ASD system

The study was forty minutes total per participant and consisted of an in person meeting where they viewed a twelve-minute VR experience and answered six follow up questions. All interviews were conducted in various locations across the City of Toronto.

LIMITATIONS OF THIS STUDY

Although this study reached its aims, there were unavoidable limitations that can be categorized as either “study design” or statistical/data limitations. First, because of factors including being to the end of fiscal year and a lack of process to approve a request for participation in a VR study such as this. This research was conducted with a smaller sample size than intended. Therefore, to generalize the results, future studies should endeavor to better understand current processes within organizations and account for time requirements necessary for broader participation. In addition, the design of the VR prototype was limited by restricting filming options to not include vulnerable persons and environments.

INTERVIEW QUESTIONS

Table 6: List of Interview Questions and Rationale

#	**Question**	**Rationale**
1	What are your initial reactions or thoughts?	To determine how impactful the prototype was and capture any initial reactions from participants to gauge immediate impact
2	Was the format of VR effective in giving you some understanding my lived experience?	To assess if the format chosen was effective or not in conveying a sense of my lived experience
3	Did you feel a sense of presence when experiencing the content?	To determine the level of presence felt by participants.
4	Does this lived experience experiment give you ideas as to how VR could be used in design of ASD services? If so how, if not, why not?	To assess if the format chosen could be a tool for understanding lived experiences for the system as a whole.
5	How could this technology and content like this prototype potentially support your direct line of work with clients and their families in the near future?	To assess if the format chosen could have a direct impact on the participants day to day work as opposed to ideas about the system.
6	What about 10-20 years?	To seek insight and signals for futures building scenarios
7	What are the immediate barriers for this technology to be adopted in this system as a lived experience tool?	To determine barriers of adoption, implementation and acceptance in human services systems
8	What other ways might this technology be of value to the design of services in this system or your profession? Or closing thoughts?	To provide participants with an opportunity to share their own ideas for other potential uses of VR beyond the scope of this study (a lived experience tool).

PARTICIPANTS

The recruitment of professionals within the ASD system in Ontario was ambitious in an attempt to have a diverse group of roles and perspectives. Participants were obtained through recruitment efforts that included email correspondence, posters and telephone. The following is a list of participants

Table 7: List of Study Participants

Participant	Role
Aviva Goldberg	Director, Works of Wonder (Home Based ABA Programming)
Name Requested Not To Be Disclosed	Private Practicing Social Worker
Dr. Yona Lunksy	Clinician-Scientist in Adult Neurodevelopmental Services and Director of the Health Care Access Research and Developmental Disabilities (H-CARDD) Program at the Centre for Addiction and Mental Health (CAMH)
Dr. Lora Appel	Research Fellow , Open Lab (University Health Network)
Dr. Kevin Stoddart	Director, Redpath Centre Private mental health organization specializing in ASD and other neurodevelopmental conditions, providing a range of clinical services, research, educating stakeholders, and advocating for systems change.
Name Requested Not To Be Disclosed	PhD Student
Geetha Mooray	Founder and Executive Director of the South Asian Autism Awareness Centre
Kingston Yogendran	Communications Coordinator (South Asian Autism Awareness Centre)

SUMMARY AND ANALYSIS OF FINDINGS

Interview results were transcribed and categorized in a table format *(See Appendix D)* in an attempt to synthesize and discover correlation to the study's purpose. In my dispassionate summary and analysis of study results, it remains unclear if Virtual Reality technology has immediate implications as a design tool for family/caregiver lived experience(s) based on the prototype used in this study. However, the study garnered powerful insights that will have implications on futures thinking.

Since VR and other immersive reality technologies are still in the early stages of their development, this was not a surprising result. However, the factors contributing to my assessment came as a great surprise in a number of ways. First, my initial assumption entering this study was that the format I chose of recording a caregiver using a 360-degree camera and producing a VR experience would be seen as an immediately powerful and moving format by study participants. Participants all agreed they felt a degree of presence during the experience,

"Yeah, I felt like I was in the room. I felt like I could get up and walk around."(Private Practicing Social Worker, personal communication, March 23, 2017) However, deeper analysis of the results reveal a tension regarding the prototype itself. This tension existed between those who work in traditional roles within Ontario's ASD system and those who work directly with families in more of an advocacy/direct support role. Participants working in the system as practitioners seemed to want a deeper level of immersion and presence related to a crisis moment instead of the linear monologue storytelling method presented in the prototype. Examples provided during interviews are as follows:

I **want to feel the stress that you feel about the changes that are gonna happen for him"**

(A. Goldberg, personal communication, March 20, 2017)

"I**f you do a part two you really want to also look at "I've chosen what you look at versus I can explore at my own pace version. Us being you experiencing the space as opposed to us watching you"**

(Y. Lunsky, personal communication, March 24, 2017)

In contrast, study participants who work in the system as advocates were more enthusiastic about the prototype overall as a tool for immediate use to support advocacy, education and fundraising efforts.

> **Very neat. You got me thinking about lots of things. So obviously potentially a great tool for the following areas: Practice, research and policy development. I think that the application would be even greater if we look at multiple players and look at a variety of environments. There are all kinds of applications**
>
> (K. Stoddart, personal communication, March 27, 2017)

> **This is great. I loved it because I think there is a way of getting an inside look of what happens in the house. and also it's very hard to catch those moments. To talk about feelings and talk about emotions and this is the best way and it touches people's hearts. So I think this is a great thing**
>
> (G. Morray, personal communication, March 31, 2017)

I believe the significance of this tension is that it provides evidence that suggests those who work within the system closer to the design process require more visceral interactive storytelling formats in immersive reality technologies instead of passively being an observer. Conversely, those who work in the system which include an advocacy role were more seemingly able to accept the prototype as an almost immediate remedy to improve advocacy efforts, education and potential as a fundraising support tool. When asked if the medium of VR was effective in giving an understanding of lived experience participant results varied from wanting more to creating an emotional connection.

I think the setting limited you. We weren't seeing you interact with your mom or brother (for example having supper). That would be where the real gold is at for me. You sitting in the room are very poignant, So I think that's the future for VR if we get to that point is how we can really find the settings and the environments
that would be most helpful.

(K. Stoddart, personal communication, March 27, 2017)

We are in this field as well and we see many parents so this created that emotional connection(G. Morray, personal communication, March 31, 2017)

When asked if the prototype generated ideas for how VR could be used in the design of ASD services there were multiple ideas that highlighted its promise as a design tool.

> **I think two things. 1. Hearing from a family member perspective is really important. I think it's also having VR gives it that snapshot of what it actually looks like. I also think about the school system and how it can be used there. I think about the community I think about how VR could be used as a narrative to tell someone's lived experience around their special needs family member. I think about stigma breaking**
>
> (Private Practicing Social Worker, personal communication, March 23, 2017)
>
> **if you could just capture some of these moments so that policy makers who don't necessarily have experience with specific health care situations can actually understand. Maybe you talking about it is still too similar to me talking about it like we are now but if I was in the environment capturing something I wouldn't otherwise see so easily I think it would be an effective tool.**
>
> (L.Appel, personal communication, March 30, 2017)
>
> **I do mainly grant writing and marketing fundraising. So I can see how this tool can be very powerful to bring on sponsors on board. For people who are not associated with this field and we approach them this would be a powerful tool to say this is our centre this is**

what our parents go through it would bridge a lot between us and sponsors

(K.Yogendran, personal communication, March 30, 2017)

Dr. Lora Appel provided the most poignant response for the central question of this project confirming that VR could indeed be a tool to support the design of services.

> A lot of policy makers I know even within the hospital share that when a program is supported or changed their info is based on a lot of number crunching and statistics. I definitely see the value in it [VR] since we're trying to create the greater good for the greatest amount of people and so you're going to need some generic generalizable information. But the human aspect can really affect someone. So if you're trying to affect change and really show it's good to personalize things with stories (personal communication, March 30, 2017)
>
> This demonstrates a readiness and willingness to embrace the potential of immersive reality technologies as a possible design tool which could have futures implications.

Implications for Possible Futures

Insights extracted from study results that have implications for the future (10-20 years) show the inevitability of VR and immersive reality technologies becoming an integral part of the design of services within human services systems. I come to this conclusion in part because of the rich ideas generated via the study by participants. These ideas included the potential for VR and other immersive reality technologies as possible tool for:

- Co-creation between end users
- Research
- Video self-modeling
- Site visits and the design of spaces
- Preparing families
- Advocacy
- Education of staff who do not have exposure to families/caregiver experiences

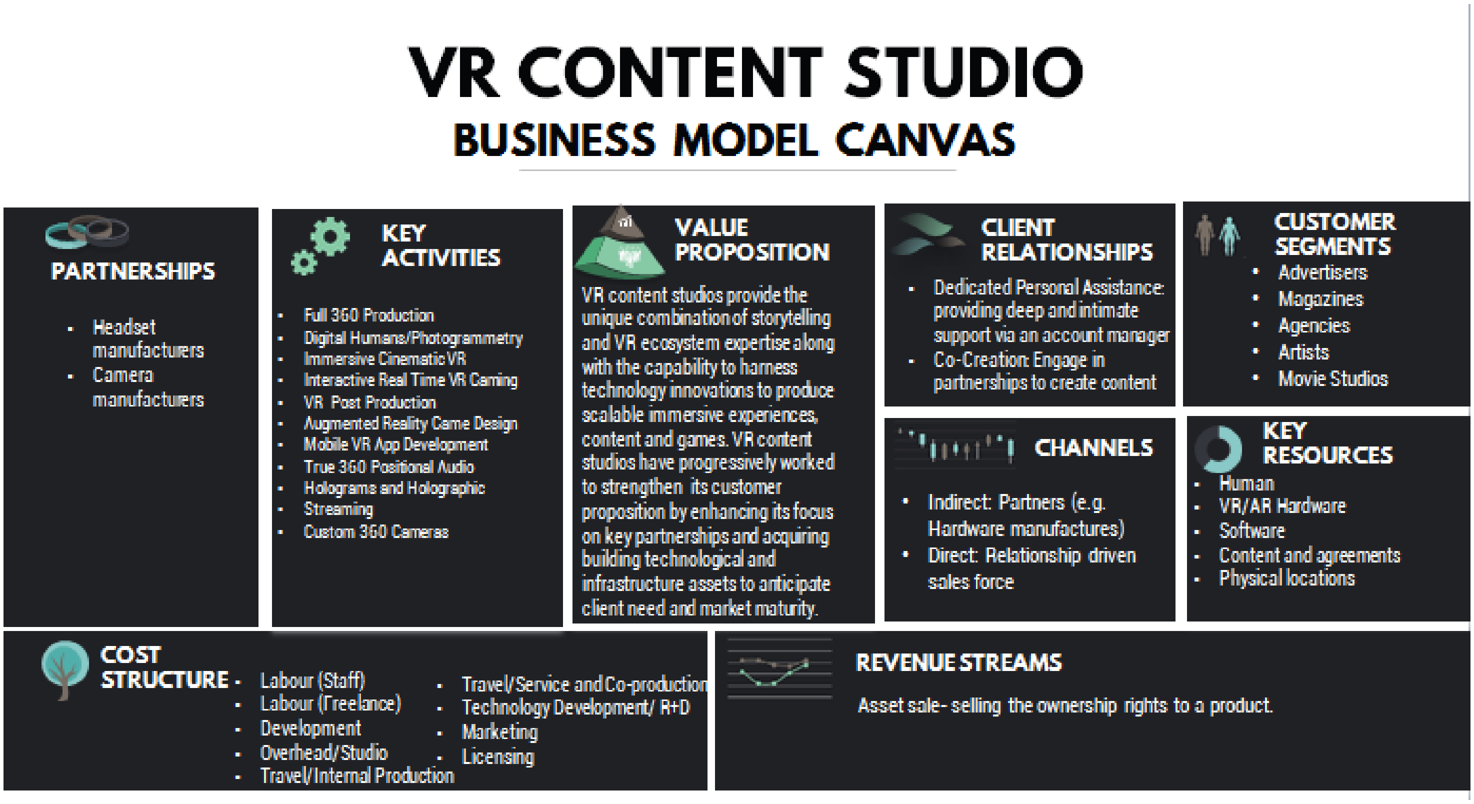
Even though the majority if ideas participants provided are beyond the scope of VR as a tool for recording and sharing the lived experience of families/caregivers, the ideas articulated provide signals that show a system need to broadly embrace innovative, immersive and human centred based storytelling formats to affect various areas in the service design process. Therefore, future implications are not just limited to the lived experiences of families and caregivers.

The most surprising to me, in terms of futures implications, was the sense of increased agency I felt as a caregiver in the ASD system meeting with professionals. I felt like each meeting inverted the traditional power distance relationship of expert speaking to client. The format of the study led by me capturing, editing and showcasing my lived experience, in my own context, on my own terms, then demonstrating the final product to professionals, enabled a feeling that my lived experience was a source of power beyond its immediate cathartic benefits. In other words, I believe this study has the possible ability to disrupt the power distribution between end users (including families/caregivers) and policy developer/practitioner. Additionally, the study results also revealed signals that may have future implications for those who are most marginalized in human services systems who traditionally have little opportunities for their voice to be heard (including new immigrants). Enabling marginalized communities and individuals in human services systems either to create for themselves or to co-create VR or other immersive reality experiences may enable greater self-advocacy efforts and increased agency.

Implications for Disruption

Cost and educating system actors (including families and caregivers) were key barriers identified for adoption of VR in the design of services during this study. While, at first glance, these factors are indeed current barriers of adoption for the average person to enter the VR content creator space, a surprising insight I did not expect is that these barriers also contain inherent threats to disrupt the expertise that VR studios currently maintain in the production of VR experiences. This possible implication is based in part by Moore's Law which Molik (2006) defined as the speed of computers, as measured by the number of transistors that can be placed on a single chip, will double every year or two and has been credited with being the engine of the electronics revolution. Therefore, the expected cost reduction and ubiquity of VR equipment will make the technology easier to use, affordable and more widely available. Thus, creating more opportunities for those in the ASD System (including families /caregivers) to produce their own experiences, like I did, without the need for support from a VR studio. To further investigate this potential implication I created a business model canvas prototype representing the current state for a typical VR content studio in 2017.

Figure 1: Image of Generic Business Canvas for Typical VR Studio



VR CONTENT STUDIO

BUSINESS MODEL CANVAS

PARTNERSHIPS

- Headset manufacturers
- Camera manufacturers

KEY ACTIVITIES

- Full 360 Production
- Digital Humans/Photogrammetry
- Immersive Cinematic VR
- Interactive Real Time VR Gaming
- VR Post Production
- Augmented Reality Game Design
- Mobile VR App Development
- True 360 Positional Audio
- Holograms and Holographic
- Streaming
- Custom 360 Cameras

VALUE PROPOSITION

VR content studios provide the unique combination of storytelling and VR ecosystem expertise along with the capability to harness technology innovations to produce scalable immersive experiences, content and games. VR content studios have progressively worked to strengthen its customer proposition by enhancing its focus on key partnerships and acquiring building technological and infrastructure assets to anticipate client need and market maturity.

CLIENT RELATIONSHIPS

- Dedicated Personal Assistance: providing deep and intimate support via an account manager
- Co-Creation: Engage in partnerships to create content

CUSTOMER SEGMENTS

- Advertisers
- Magazines
- Agencies
- Artists
- Movie Studios

CHANNELS

- Indirect: Partners (e.g. Hardware manufactures)
- Direct: Relationship driven sales force

KEY RESOURCES

- Human
- VR/AR Hardware
- Software
- Content and agreements
- Physical locations

COST STRUCTURE

- Labour (Staff)
- Labour (Freelance)
- Development
- Overhead/Studio
- Travel/Internal Production
- Travel/Service and Co-production
- Technology Development/ R+D
- Marketing
- Licensing

REVENUE STREAMS

Asset sale- selling the ownership rights to a product.

Source: This Author

The combination of lower barriers to entry and the more society shifts toward creating content based on lived experiences (including individuals like myself) the more potential disruption for VR content studios in the areas of Partnerships, Customer Segments, Key Activities. This will undoubtedly force them to constantly reimagine their value propositions.

RECOMMENDATIONS FOR FUTURE RESEARCH

Based on the literature reviews, prototype creation, expert interviews and analysis conducted in this project the following suggestions are recommended themes for future research:

- Exploring how best practices learned in the field of digital storytelling can be applied in the creation of lived experience projects using VR and other immersive reality technologies
- Conducting expert interviews and prototype workshops with individuals who work in policy design roles for human services systems including ASD
- Co-Creating another proof of concept, immersive reality experience with marginalized populations to determine if the skills learned and executed increases sense of agency
- Conducting a workshop with policy designers to provide them with the skills to create immersive reality experiences for potential policy innovations. This research would determine if immersive reality technologies can be used as an internal tool to better communicate policy submissions
- Conducting longitudinal studies on how lived experience storytelling, created and viewed using immersive reality technologies, affects sense making of policy designers working in human services systems

- Researching the working environments of individuals who design and or influence the design of services in human services systems. The goal of this study would be to determine in what ways should working environments be redesigned to better integrate the use of immersive reality technologies to be accepted in the workplace. Further research would determine the appropriate integration into daily workflows using empathy journey mapping techniques
- Exploring how the *Technology Acceptance Model* (Davis, Bagozzi, & Warshaw, 1989) applies to human services systems and immersive reality technologies
- Exploring lived-experience-based immersive storytelling and its impact on sense making for Masters and PhD students seeking policy design careers
- Experimenting with how immersive reality content developers would be embedded into a policy development of human services systems working environment. Then embedding a policy designer in an immersive reality content studio to determine which skills and capabilities are most desirable to have and which as most transferrable
- Determining the potential for immersive reality technologies as a foresight tool building possible futures scenarios for human services systems.

INNOVATION PLAN

The following section will attempt to highlight and summarize some key considerations in pursuit of a germane and actionable implementation strategy to embed immersive reality technologies in the design of human services.

1. Recognition that those living with experiences as consumers (either as parents/caregivers or with a diagnosis) in human services systems also work within them. Therefore, these individuals are uniquely positioned to support future exploratory projects attempting to integrate immersive technology and lived experience. Further to this, there would need to also be caution to not have further bias based on individual experiences.
2. Being very mindful and respectful of the fact that individual experiences should not be over sensationalized when used as the basis for immersive reality content.

Personally, I intend on an innovation plan that includes the following:

1. Seeking keynote presentation opportunities to share my process and insights

2. Cultivating partnerships with immersive technology studios to collaborate on future projects to develop ideas put forth in this project.

The limits of the possible can only be defined by going beyond them into the impossible.

Clarke, (1962)

CONCLUSION

In closing, as society enters a potentially transformative and unprecedented era of uncertainty, marked by the rise of Artificial Intelligence (AI), machine learning and immersive reality technologies, the impacts on humanity cannot be predicted. However, what can be expected / worked toward is the need for human services systems (including the ASD system in Ontario) to be responsive in their service designs to better support individuals and their families/caregivers. This project began with the goal of exploring how the emergence of immersive reality technologies including VR could potentially support the design of human services systems in the future. Through my journey of identifying, harnessing, capturing and creating I have learned that it is the power of one's lived experiences and the ability to share one’s stories in an impactful way that holds the key to innovation. The power of lived experience as the engine of storytelling not only holds the key to innovation within human services design but also potentially threatens disruption in the immersive reality industries that help to give it a voice. Like David versus Goliath.

“This is not the end, it is not even the beginning of the end, but it is perhaps the end of the beginning”

(Churchill,1942)

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APPENDICES

Appendix A: Consent Form

Appendix B: Recruitment Poster

Appendix C: Transcription of Interviews

Appendix D: Additional Unused Materials

APPENDIX A: CONSENT FORM

Invitation / Consent Form Template

Date: **November 28, 2016**
Project Title: **Mobile Eyes For Change:** The Future of Immersive Technologies and The Design of Human Services

Principal Investigator:	Faculty Supervisor (if applicable):
Shawn Hewitt, Student	**Greg Van Alstyne**
OCAD University	Faculty of **Strategic Foresight and Innovation**
	OCAD University
	(416) 977-6000

CONFIDENTIALITY

The information you provide will be kept confidential, i.e. your name will not appear in any thesis or report resulting from this study. However, with your permission attributed quotations may be used. Shortly after the interview has been completed, I will endeavor to send you a copy of the transcript to give you an opportunity to confirm the accuracy of our conversation and to add or clarify any points that you wish.

☐ Yes, I wish to be attributed for my contribution to this research study. You may use my name alongside statements and/or quotations that you have collected from me.

DATA COLLECTION

Data collected during this study will be stored on a hard drive locked in a drawer that requires a key. Data will be kept for 365 days after which time the data will be destroyed. Access to this data will be restricted to myself and Greg Van Alstyne (my primary advisor)

VOLUNTARY PARTICIPATION

Participation in this study is voluntary. If you wish, you may decline to answer any questions or participate in any component of the study. Further, you may decide to withdraw from this study at any time, or to request withdrawal of your data (prior to data analysis occurring in February 2017) and you may do so without any penalty or loss of benefits to which you are entitled.

PUBLICATION OF RESULTS

Results of this study may be published in [select from among: reports, professional and scholarly journals, students theses, and/or presentations to conferences and colloquia]. In any publication, data will be presented in aggregate forms. Quotations from interviews or surveys will not be attributed to you without your permission.

Feedback about this study will be available by contacting Shawn Hewitt. Feedback will be available as of July 2017.

CONTACT INFORMATION AND ETHICS CLEARANCE

If you have any questions about this study or require further information, please contact the Principal Investigator (Shawn Hewitt) or the Faculty Supervisor (where applicable) (Greg Van Alstyne) using the contact information provided above. This study has been reviewed and received ethics clearance through the Research Ethics Board at OCAD University [file #100887]. If you have any comments or concerns, please contact the Research Ethics Office through cpineda@ocadu.ca.

CONSENT FORM

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

Name: ___________________________

Signature: ___________________________ Date: ___________________________

Thank you for your assistance in this project. Please keep a copy of this form for your records.

APPENDIX B: RECRUITMENT POSTER

PARTICIPANTS NEEDED

CAN VIRTUAL REALITY EXPERIENCES SUPPORT YOUR WORK?

AS A PARTICIPANT YOU WILL BE ASKED TO VIEW A BRIEF VIRTUAL REALITY EXPERIENCE AND COMPLETE INTERVIEW QUESTIONS.

YOUR PARTICIPATION WILL INVOLVE ONE 40 MINUTE IN PERSON SESSION

FOR MORE INFORMATION,
OR TO VOLUNTEER
PLEASE CONTACT:
SHAWN HEWITT
[redacted]

THANK YOU FOR YOUR RESPONSES. PLEASE NOTE THAT PARTICIPANTS WILL REQUIRE BOTH EARS AND EYES TO BE FUNCTIONING

VIRTUAL REALITY CONTENT HAS BEEN KNOWN TO PRODUCE VARIOUS RANGES OF MOTION SICKNESS WITH CONTENT THAT RELIES ON QUICK MOVEMENT AND SIMULATIONS LIKE ROLLER COASTERS. THE EXPERIENCE RECORDED WILL NOT BE GREATER THAN PARTICIPANTS WOULD EXPECT IN NORMAL LIFE.

APPENDIX C: TRANSCRIPTION OF INTERVIEWS

Question 1

What are your initial reactions or thoughts?

Table 6: List of Responses For Question 1

Participant	Answer
Aviva Goldberg, Private Practicing Social Worker working in Toronto	“It's interesting. to get a glimpse into the room. What it was like before. I almost wanted to see it the opposite way. What his life was like before and then into the transition to the new room. Because it would give a sense of the sterility. His room had a character to it that the group home did not that you guys tried to bring in. There's a piece of me that wants to see the actual move in process. Also, as a caregiver if I really wanted to know what I was getting myself into and what the steps are I could see how this could be useful (i.e. sitting in on the interview, the intake etc.) with me going through all the steps with you. Being able to see the move in period and then seeing your brother and then how did your brother respond to the room. Not that everyone's experience is going to be the same but it will at least allow for a caregiver who has nine million questions and anxiety about my child into this place so I think if I saw the steps my anxiety might be lessened. I agree that it is isolated. It would be good if there was a caregiver piece to say ok, now what is my role?” “What really landed with me is your talk about being in the sandwich generation. Where you have this brother that you need to make sure that he is on track and the fear and anxiety of him moving to the next stage. Also what that means for your mom. She has had an adult kid so that’s a huge transition for her to go through. So you're thinking of both of them plus what it means to you and your family right. Even though the change with your brother is good it's also a change so it evokes a lot of anxiety and fear around that.”

Participant	Answer
Dr. Yona Lunsky	Very interesting. I don't think you did a whole lot with it but it was interesting to watch you have a moment in time. Whether it was being in your brother's room, calling to your mother, reading the letter then taking a breath before you step into the room, seeing the lava lamp and the fan. We wouldn't get that if we were just meeting and talking to you.
PhD Student	I was wondering what VR added. The words were powerful. It would have been a very powerful transcript. I'm not sure looking around the room added to that effect.
Dr. Lora Appel	Interesting, in terms of just the graphics. I know a bit about VR having experienced it. I feel it would have better if I could have seen more of your facial expressions. That would have helped even to feel if it was closer. Closer would have been better to arouse emotion. I thought it was interesting when comparing the two rooms right away I could see similarities. I think there is a potential for VR to do that I'm not sure in this film that it came out so much but I know its trial 1. I think maybe if you having an interaction between you and your mom it would have been better. Also because it's not like policy makers have endless amounts of time so you have to give it to them a bit faster and that would be good. Some things were interesting. Mostly comparing the rooms and seeing they had the same elements (one of them was a bit more lived). Those are my initial thoughts.
Dr. Kevin Stoddart	Very neat. You got me thinking about lots of things. So obviously potentially a great tool for the following areas: Practice, research and policy development. I think that the application would be even greater if we look at multiple players and look at a variety of environments. We have your experience. What is your brother's experience? What is your brother's experience with you interacting with him? For example, placements. Could this be part of a file where we see a VR experience? Could it be used in diagnosis? I am really quite appalled that we have not brought technology to bear on the issue of diagnosing kids and adults with autism. So we still get somebody in a sterile office environment, lots of checklists for parents and individuals. So how can we use VR to assess an environment and people’s interaction in their own context? We also know specific to ASD people have issues generalizing treatment gains from the office to the real environment. I don't care if someone can use CBT with me I want them to be able to use it when they are about to have a meltdown. If they can't use it then then my intervention has not been effective because you can know all about the techniques and not have the

	ability. For example, how does a caregiver prompt someone to use CBT? Individual experience family experience and sibling experience are very critical. The family is the client! So we think that people with ASD are operating in a vacuum and there are no issues with family (Aging parents, etc.) and the onus is on siblings to take care. There are all kinds of applications.

Participant	Answer
Geetha Mooray	This is great. I loved it because I think there is a way of getting an inside look of what happens in the house. and also it's very hard to catch those moments. To talk about feelings and talk about emotions and this is the best way and it touches people's hearts. So I think this is a great thing
Kingston Yogendran	That was amazing!

Question 2

Was this medium effective in giving you a some understanding my lived experience?

Table 7: List of Responses For Question 2

Participant	Answer
Aviva Goldberg, Director Works of Wonder (Home Based ABA Programming)	I think I wanted more. I felt like I was watching a video of you talking. It did not need to be virtual reality. I could have been watching a video of you talking and have the same experience. It would have been more beneficial to walk me through the process.
Private Practicing Social Worker working in Toronto	Yes. It was nice to follow you as you went through that stage but also came back to the house and saw where he kind of took off from so um yea I thought it was really neat.
Dr. Yona Lunsky	I think so. I think the question is how much more? It would be interesting if you were to update your study to have people randomly, reading the transcript, watching a 2D video or using VR. So it was effective but I'm not sure how much more it added. I think it was interesting but I can't tell you how much more.
PhD Student	Yes
Dr. Lora Appel	I don't know so much this clip. I do think it has potential but you told me you were stressed but I'm not sure I felt stressed.
Dr. Kevin Stoddart	Yes, it was but I think it was minimally effective. I think the setting limited you. We weren't seeing you interact with your mom or brother (for example having supper). That would be where the real gold is at for me. You sitting in the room are very poignant, So I think that's the future for VR if we get to that point is how we can really find the settings and the environments that would be most helpful.
Geetha Mooray	Yes, for sure. We are in this field as well and we see many parents so this created that emotional connection

Kingston Yogendran	Yes. Obviously as you develop this thing you would want to go beyond talking to the camera to showing the day to day when talking about moving brother. It was powerful hearing your experiences but then for the user to start going through that with me would be very powerful

Question 3

Did you feel a sense of presence when experiencing the content?

Table 8: List of Responses For Question 3

Participant	Answer
Aviva Goldberg, Director Works of Wonder (Home Based ABA Programming)	Yes
Private Practicing Social Worker working in Toronto	Yeah, I felt like I was in the room. I felt like I could get up and walk around and its funny because I almost felt like I wanted to get up and start walking around and walk out the door to see what else existed
Dr. Yona Lunsky	Yes
PhD Student	Mild yes
Dr. Lora Appel	Yes
Dr. Kevin Stoddart	Yes
Geetha Mooray	Yes
Kingston Yogendran	Yes

Question 4

Does this lived experience experiment give you ideas as to how VR could be used in design of ASD services? If so how, if not, why not?

Table 9: List of Responses for Question 4

Participant	Answer
Aviva Goldberg, Director Works of Wonder (Home Based ABA Programming)	It would be amazing (because most people on the spectrum are visual thinkers) to visually walk through the changes they are going to make in their lives before they actually had to do it. A good example of where I struggle a lot is most of the clients (youth) we work with have trouble with airport security. Airport security does not let you go and visit and practice. If there was a VR experience of me going through airport security what it felt like to give up something of my own (not allowed to hold favourite toy, give shoes, i.e. things that would be upsetting) If I get to walk through and get to practice it virtually before I had to do it. That's amazing.
Private Practicing Social Worker working in Toronto	I think two things. 1. Hearing from a family member perspective is really important. I think it's also having VR gives it that snapshot of what it actually looks like. I also think about the school system and how it can be used there. I think about the community I think about how VR could be used as a narrative to tell someone's lived experience around their special needs family member. I think about stigma breaking. Education and knowledge transfer is another area. If you feel like you're immersed in someone's story and someone's narrative. I think it can be used across multiple domains.
Dr. Yona Lunsky	Yes, lots of great ideas. I think it's very good in terms of proof of concept seeing it. I think it could. For example someone is coming into the emergency department after destroying the house. if the family has a sense of capturing what the space was like that would be very effective. If you live in a noisy or stressful environment you could get a feel for that. You could potentially watch and potentially have the sensory experience. Certainly for people who are moving for example I could have a look around to see what the space is going to be like. It could be a safe way potentially to introducing or showing them a situation. I also think maybe for example I could see where your brother was living before and I could use that in what I design for him later. But you'd have to ask how is it different than just going and visiting a

	place? Although if I can't get to that place I could get a feel for it.
PhD Student	Did not answer
Dr. Lora Appel	I definitely think that there is a potential. Um I think it's more to capture realistic interactions like (What would stress me out having a person that doesn't live in such an environment is to actually see a moment of crisis. Recently I was on the subway in NYC and there was a father whose son was clearly on the spectrum he wanted to ride the trains wanted to ride to the end and the father was having discussion in public and I was thinking the father is doing a really good job at trying to de- escalate the point of crisis. Maybe It would be interesting if you could just capture some of these moments so that policy makers who don't necessarily have experience with specific health care situations can actually understand. Maybe you talking about it is still too similar to me talking about it like we are now but if I was in the environment capturing something I wouldn't otherwise see so easily I think it would be an effective tool.
Dr. Kevin Stoddart	Yes, but I think the challenge will come with paring the VR developer with a clinician so I think starting out with a discrete clinical situation can be used in that format. like diagnosis. how a kid is playing with a peer. I think we need to have the clinicians speaking to the developers.
Geetha Mooray	So I can say both ways yes it will help us to deliver the message because we do too many things in here at the centre. We do a lot. So it's like we do therapies and we train volunteers. So maybe volunteer training can be done this way. It gives a lot more effective thing then being in a classroom. This one gives a lot more practical experience and also like um like for the siblings. You feel like you are there. It's a good vehicle but again it's cost that is the concern
Kingston Yogendran	I do mainly grant writing and marketing fundraising. So I can see how this tool can be very powerful to bring on sponsors on board. For people who are not associated with this field and we approach them this would be a powerful tool to say this is our centre this is what our parents go through it would bridge a lot between us and sponsors

Question 5

How could this technology and content like this prototype potentially support your direct line of work with clients and their families in the near future?

Table 10: List of Responses For Question 5

Participant	Answer
Aviva Goldberg, Director Works of Wonder (Home Based ABA Programming)	I think having an experience that I can't have in real life would be amazing. Not just people with ASD; especially people with anxiety. It could really give me a chance to do exposure. For a caregiver to walk through the questions that may be asked during intake, I can see how that would be beneficial to them.
Private Practicing Social Worker working in Toronto	We're on this interesting cusp right now because of the clients that I see are having tech over use and gaming addiction (or like social media) and within the clients that I see that are experiencing excessive behaviour around tech there's a certain profile. We see a lot of neurodevelopmental disorders with the profile that we see and. we meet a lot of these clients face to face. I always think about “hey wouldn't it be great if we reached them in terms of where They're at online (email, texting, Skype, all of these things that would give us greater access to potential clients. Right now we're just using one medium. They come in ...we do face to face. Once in a while we may do phone counselling but not very often.
Dr. Yona Lunsky	In psychology generally we have people with different ranges of anxieties having exposure so we use virtual reality as a way of exposing people to situations they are afraid of. With people with autism for example a lot of stress and you need lots of practice so using this type of technology will allow people to practice or get use to certain kinds of situations. Even just some of the work I do is with people who go to emergency department. So we have a two dimensional set of ten pictures that tell a social story of what to expect when you go to the emergency room/emergency department. If I wanted to see myself in that situation to understand how I feel. There was something they did 15 years ago. Say I'm trying to learn a skill "How to take the bus to go to work or wherever" or trying to learn how to put the dishes away that I will be coached on each step and someone would put all those steps together into a video so I could watch myself doing a skill that I don't actually have the skills yet to do and then I would learn it by watching myself. So I could imagine VR showing me clips put together of me in that situation or even to see "WOW I did it. I'm so proud that I did it and that I can watch it over and over again to remember how I do it and how I handle when people are noisy and I have to tell them please be quiet without hitting them or whatever. I could see myself in that

	situation Though I'm not so sure if it would make sense to see myself or see people around me and hear myself. Like how would you use VR to immersive yourself in a situation (The technique is called Video Self Modelling). Would you watch yourself video self-modelling or would you just watch everything around you as though you were doing it.
PhD Student	In terms of clinical presentations and different issues that may not present in an office that are hard to describe, assessments to help professionals better understand
Dr. Lora Appel	A lot of policy makers I know even within the hospital share that when a program is supported or changed their info is based on a lot of number crunching and statistics. I definitely see the value in it since we're trying to create the greater good for the greatest amount of people and so you're going to need some generic generalizable information. But the human aspect can really affect someone. So if you're trying to affect change and really show it's good to personalize things with stories. It’s always good to have. Have your numbers have the paper that talks about stats on the side saying here's what it looks like in reality for someone. and I think that's the power of Virtual Reality because watching a film is also very good but it doesn't make it quite as immersive as we know are the benefits of VR. For example when you put the headset on and there is no horizon line other than the one you are in you're instantly immersed irrespective of the quality of the film and so someone really will get a better impression of what it's like to have that lived experience. I mean really you're looking at something from the perspective of the person. I think it would be helpful I don't know to what extent to co-create content with not only caregivers (while important because they are often overlooked as members of the healthcare system) but also as patients /clients as they are called.
Dr. Kevin Stoddart	Yes but I think the challenge will come with pairing the VR developer with a clinician so I think starting out with a discrete clinical situation can be used in that format. like diagnosis. how a kid is playing with a peer. I think we need to have the clinicians speaking to the developers.
Geetha Mooray	Wanted the previous answer to question 4 to be used here as well
Kingston Yogendran	I’m looking at stuff like volunteer training. In our centre a big part of what we do is training volunteers in the community to work with families and people with ASD. So when they come in they have no experience. So we can put something like this on them and say hey this is what it's like. This is how a session will go. So it would be a great teaching tool.

Question 6

In the previous question you were asked about how this technology and content like this prototype could potentially support your direct line of work with clients and their families in the near future. Now what about in 10-20 years?

Table 11: List of Responses For Question 6

Participant	Answer
Aviva Goldberg, Director Works of Wonder (Home Based ABA Programming)	Find answer
Private Practicing Social Worker working in Toronto	It makes me think, “Could we reach a bigger market of clients through using different mediums like VR?”
Dr. Yona Lunsky	They could see or experience what something is like to prepare them for it and also if they have access to the technology they could show us what some things are like so we can understand the situation.
PhD Student	I think the different environments that this could generalise to. Thinking about a client I was working with she was going on a trip and going through airport security is going to be a huge ordeal for her. So I guess just generalizing to different environments.
Dr. Lora Appel	The tech will be way better. I could easily see you capturing like if we have it built into our glasses we wouldn't need even have to work so hard (to set up the camera) just take a clip of your life and have somebody else view it umm or experience it.
Dr. Kevin Stoddart	I think the applications are limitless. In assessment and in research or particular programs. The challenge for us in a clinical setting is the time it takes us to go out somewhere. For me to see a kid in his classroom is a big bill. And so but if the kid is having difficulty in the classroom that would be important for me to observe him in the classroom. Where do we really need to understand the environment as it relates to the kid? That’s the sweet spot of virtual reality isn't it?

Geetha Mooray	Technology will develop more than what we have. My passion is about dance and so that might be the best thing to do. So when I teach them and they come back a week later it's not the same thing. So maybe if we can use VR and explain step by step and they learn and start practicing the children.
Kingston Yogendran	Endless possibilities. I would say teaching. I'm also thinking about the diagnosis clinic. Cause right now we are running a program that has parents from the community. We are the first contact with them like right after diagnosis or leading up they come to us with what's going on?" If we can expose them to VR and show them this is a similar experience to what another family had I think it would mitigate the fear they have.

Question 7

What are the immediate barriers for this technology to be adopted in this system as a lived experience tool?

Table 12: List of Responses for Question 7

Participant	Answer
Aviva Goldberg , Director Works of Wonder (Home Based ABA Programming)	I think the barrier for me is that I was watching you but not being you. I wanted to be you. Follow you along in your path and watch what you were doing. Not just watch you talk about it. Like If I'm a policy maker I can have someone come into my office and interview but I don't really get what it's like to be me. I understand a little bit more because what I do for a living because I have empathy for you. You saw, me nodding and understanding why your brother had a fan in his room. One of the things I noticed is the radio in his room and why that is important to him. But the stereo is gigantic. Probably not a big deal for some people but for me (I was like there's no TV in his room). I noticed the absence of what was there. It was a very different space. Because I was listening to you and not you. It would have been easier to hear you and having you taking me through objects and what the difference would be for my brother and what the anxieties were around my mother.
Private Practicing Social Worker working in Toronto	I think of ethics and confidentiality/anonymity. Those kinds of things. Probably the tech itself including training. But those are small barriers I feel. There's a lot of us that are in this field that push for things like this because we know we want to reach a bigger population
Dr. Yona Lunsky	I think others don't know about it. Cost. Fear of nausea. Thinking it's just kind of weird and people might wonder how is this any different or better than watching a film. If I could show you a video of you sitting in a room and telling me about what's going to happen. VR could be seen as just a fancy extra.
PhD Student	I think what was really powerful about what the video was the words and the message behind them. And I'm not sure if that much more was gained from VR.
Dr. Lora Appel	For one people don't even know what it is. In healthcare specifically this is changing the more conferences I attend and I talk about VR people see it and they are

	curious to know what it is and even those skeptics once they wear the headsets. This is different because I'm using it more as a treatment or a therapy where as you are using it as a conduit for impact and so the people that are putting it on (let's say are cognitively aware but there's a tendency to not like technology) I would say. There are technophobes generally in healthcare and maybe this idea of commodifying someone's experience also is not desirable. I would say those are big barriers but I think with time like the smartphone this will jump over that barrier and so I don't think there's going to be that many barriers using it as a tool for sharing information
Dr. Kevin Stoddart	Where do I start? Financial barriers. There needs to be a champion of this method. and we need funding and evaluate. so I think right now it's a proposal. a VR clip of them in their environment and we use that in assessment. Start small and start with a clinical issue and get feedback from clinicians in a standardised way. did this help? Do parents feel they have a more realistic understanding of their child?
Geetha Mooray	I can say both ways yes it will help us to deliver the message and all those things but the cost and the skills required to do it. Not everyone is tech savvy to do it. So that's the part I'm worried about because our parents right now already have trouble using the internet or to go and do some research that's a big no. you know like having trouble signing up for things online, This is a big question because we are working with marginalized communities. So that may be the only obstacle there. but otherwise if you know how to do it or train people how to do it I think it's beneficial.
Kingston Yogendran	Cost and usability. A lot of our parents are not tech savvy. So training them on this would be a challenge but the easier the tech gets the easier it will become

Question 8

What other ways might this technology be of value to the design of services in this system or your profession? Or if you have no additional ideas do you have any closing thoughts?

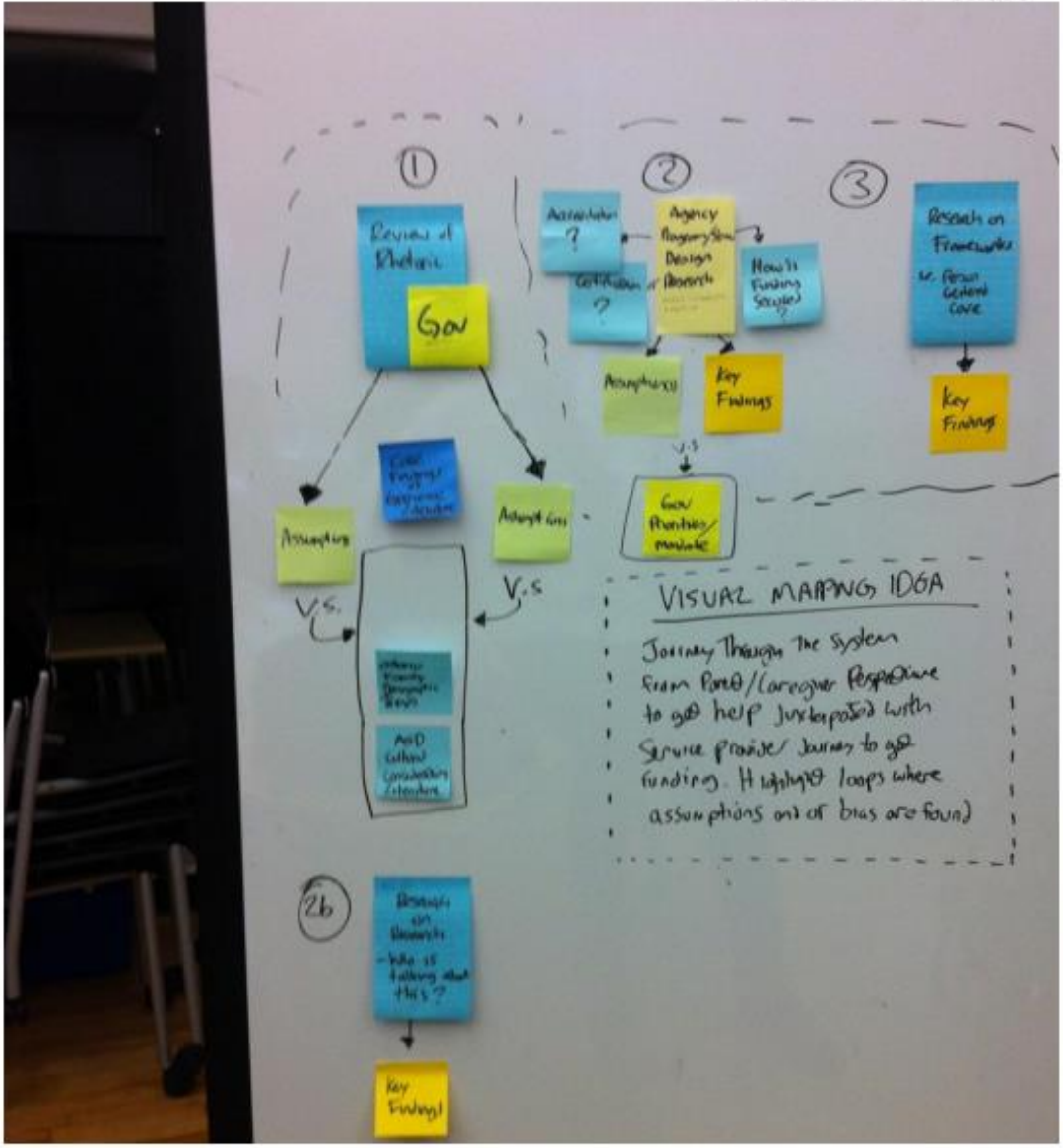
Table 13: List of Responses for Question 8

Participant	Answer
Aviva Goldberg , Director Works of Wonder (Home Based ABA Programming)	My immediate thought would be anxieties around transitions and walking people through transitions.
Private Practicing Social Worker working in Toronto	This makes me think of potential peer support programs. That really is lacking in the system today in terms of the work that we do. With our population there is some of it terms of the concurrent disorders we see addiction is often a coping strategy for what is underlying. There is lots of anxiety and depression umm you know that's also on board. there are games now that people can go through that give an experience of what depression may be like or anxiety may be like and you know it just gives clients an alternate way of seeing and or doing things and experiencing treatment and recovery.
Dr. Yona Lunsky	The question is why would you watch something in VR instead of going there. So the question is what is the barrier going there. If for example, you need 20 people going to visit a site to get a sense of what the site is like (or someone lives in the site and it would stress them if you show up. IT would be much easier to watch the video of the person in the site That would be useful. IF you need more than just reading about something and can't go there. IF it's something that lots of people have to do and it's complicated or invading someone's privacy then this could be an in between. It would give lots of people a sense of what's going on without actually having to pay to go there and invade someone's privacy multiple times. And every time we interact with it would be different and you want everyone to have the same experience (view the same thing) then it's a way to replicate or show it to lots of people. If there was a way to pseudo design something (not fully design something and see it through VR. Or can use it to

	compare. Let’s say there are three different options to try and choose the best residential setting we’ve got these three and seen it all instead of driving me to different parts of the province to look at them and getting a team of 30 people from different parts of the province if you could get piece of each one that would be powerful.
PhD Student	I think it could be an effective way of problem solving before actually implementing something
Dr. Lora Appel	One group for example that I visited to see if they would be interested or see what they are doing with VR is a group of people with severe physical disabilities and they gather once a week because they are incapable of playing instruments they play VR instruments on iPads. and they are not there to do this as music therapy they are there to have a band. each given a role and they play music together and they are all in very cumbersome wheelchairs and mobility tools and I think ... A caregiver was talking about the difficulty of the wheel trans and it's like you can talk about it but you don't understand until you live it. So if you can have these 360 cams with one of these people and live through one of their days and realize they're trying to get up and down the street and there are 3 steps that you don't even think about that they then have to go around. something like this to translate the difficulty someone has I think that's a good tool.
Dr. Kevin Stoddart	Great from a research point of view
Geetha Mooray	I was thinking about how parents and siblings are going through a lot. It's not that easy. This is something people don't realize parents go through. I just get so upset because people don’t realize and pass judgement right away. They don't know what is going on because they don't understand. The general public needs to be educated. We tell people to come here and see
Kingston Yogendran	Volunteer. Instead of relying on lecture based learning you can design service that are based on experiences

APPENDIX D: ADDITIONAL UNUSED MATERIALS

Process Review Chart



Appendix A: First Sketch of Jamshid Gharajedaghi's *Holistic Process of Inquiry* (2011).