Understanding and Overcoming the Cultural and Ethnic Stigma of an Autism/ASD Diagnosis

by

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We accept this Graduate Applied Project as conforming to the required standard.

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Abstract

In Canada, we are surrounded by an abundance of cultures and a variance of ethnic origins, which is why it is important for educators to be culturally sensitive when it comes to Autism Spectrum Disorder (ASD) and its diagnosis. The way that every culture handles an ASD diagnosis can be vastly different and this can be because one’s cultural or ethnic background, their educational background, the amount of access they have to information about ASD, how well they have been exposed to ASD in their own lives, etc. In Canada, many special education teachers are required to have a specific number of hours and/or courses on special education training - this is not a requirement in other countries and can cause an increase in frustration and a lack of overall understanding of why children with ASD act the way they do. With more knowledge and more hours of working with children with ASD, educators showed an increase in patience, understanding, and coping strategies to deal with their abnormal behaviours. In knowing this, it should not be surprising that parents and families who emigrate here from other countries do not have the same level of understanding about ASD as parents who are from North America. These parents will not have much understanding of how to help their child succeed academically and socially like they would here in North America. This project contains information about ASD and information specifically for parents, caregivers, and families of various cultural and ethnic backgrounds about cultural and ethnic stigma, under-representation, and cultural sensitivity tips. The main goals of this website and pamphlet is to relay an abundance of information in a culturally sensitive manner that is clear and concise and easy for
the parents and family members to understand. The website was created on Weebly and can be found at: https://autismstigma.weebly.com/

Keywords: autism, ASD, stigma, culture, ethnic, understanding

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Chapter 1

Introduction

Autism spectrum disorder, also commonly known as autism or ASD, has many diagnostic features that do not involve physical markers, thus making it an “invisible disability.” Individuals with an invisible disability are often misunderstood due to their “normal” physical appearance and socially inappropriate public behaviour (Chan & Lam, 2018). Some of these behaviours include, but are not limited to: hand-flapping, rocking, twirling, throwing tantrums, finger-gazing, smelling and mouthing objects, and engaging in self-destructive acts. From an outsider’s perspective, the behaviour displayed by an individual with ASD may appear disobedient and/or disruptive (Mak & Kwok, 2010). “According to the DSM-IV-TR, the diagnostic features of ASD include impaired social interactions, impaired communication, as well as restricted, repetitive, and stereotyped behaviour patterns” (Mak & Kwok, 2010, p. 2045). Parents face a unique set of challenges when a child is diagnosed with ASD, a disorder which impacts the family’s quality of life and adjustment (Tait, Fung, Hu, Sweller, & Wang, 2015). As discussed earlier, from an outsider’s perspective, the behaviour displayed by an individual with ASD may appear disobedient or disruptive, which creates a stigma that impacts not only the individuals with ASD, but also their family members, caregivers, friends, and others (Mak & Kwok, 2010). Stigma is a barrier in accessing mental health for everyone, but it is a significant impediment for racial and ethnic minorities (Anglin, Link, and Phelan, 2006). This is especially concerning in Canada, where a large portion of the population includes various cultures and ethnic groups (Statistics Canada, 2012).

A recent publication by Khanlou, Haque, Mustafal, Wazquez, Mantini, & Weiss’s (2017) study concluded that:
By 2018, over 60,000 refugee families from the Middle East, Nepal, Ecuador, Burundi, Ethiopia and Sudan will have re-settled in Canada. It is estimated that 56% of these refugees are families with children younger than 14 years of age – children who have not had access to either educational or health services for several years and parents with low literacy and language skills (Citizenship and Immigration Canada 2016). This increase in ethnic diversity of local communities impacts both the newcomers themselves and the host society with resultant implications for equitable social and health services access and provision. (p. 241).

Due to an influx in individuals from various cultures and ethnicities in Canada, there should also be a concern about equitable and accessible social and health services in the coming years. Canada has always been a very multicultural country, it has been established that parents’ beliefs predict medical decision making for their children. Although Canadian families have access to an abundance of treatment choices for their children, immigrant families and families of diverse cultural and ethnic backgrounds may not be aware of how to access these choices or how their children would benefit from these services.

Studies have shown that early intervention is crucial for individuals with ASD, but stigma can prevent families of individuals with ASD from being diagnosed at an early age (Sarris, 2015). The stigmas associated with diagnosis are different for every ethnicity and culture. Many studies have demonstrated that there is a general lack of information about ASD in non-Westernized countries and this may be contributing to the problem of failing to provide the appropriate treatment and support for these individuals. Another contributing factor may be how cultural and religious beliefs may sway parents to make certain decisions with regards to their child’s treatment and care (Alqahtani, 2012). It is very common for parents of children with ASD to be blamed by people in their community for being a direct cause of their children’s disability. This,
along with people expecting parents to have a control over their child’s atypical behaviour when out in public, creates a great deal of stigma (Mak & Kwok, 2010). In both Westernized and non-Westernized cultures, this can cause stress and dysphoria amongst parents of children with ASD, and may be a contributing factor to the willingness of parents to get their child diagnosed. Further, because information is often not available in non-dominant languages, parents from non-Western countries may not know where to start when accessing the appropriate care and help for their child. With studies showing that early intervention is beneficial for children with ASD (“Early Intervention For Toddlers with Autism,” 2009) it is important that parents from different cultural and ethnic backgrounds are given adequate and linguistically appropriate information about what ASD is, the benefits of a diagnosis, where to access treatment options, etc.

As an educator who works in and around Vancouver, British Columbia, it has been brought to my attention while working with families of various cultural and ethnic backgrounds that the notion of getting their child assessed and diagnosed by a professional to see if they are on the spectrum can be problematic. Having worked with families of a predominantly Asian background from Hong Kong or China, it was an issue that sparked interest and what influenced this project. The questions such as ‘does cultural and ethnic background play a role in whether children get designated or not?’ or ‘what are the reasons for parents from different cultures and ethnicities, specifically of Asian descent from Hong Kong or China, being so against having their child diagnosed as ASD?’ came to the forefront and influenced this project.

From experience, it seems clear that families understand that their child is different from other children at school, but they lack clarity on the reasons for these differences. If a diagnosis is made, parents often misunderstand the next steps. For example, upon creating and implementing an intervention plan for the individual with ASD, parents wonder why the plan is not working
immediately. My reflection on this is that there seems to be some disconnect between the understanding of what ASD is, what an intervention plan may look like, what an intervention plan entails, the amount of time that it will take to see results, the pace of change, and the importance of having all family members involved in the intervention.

One reason for this misunderstanding could stem from the fact that Canada and the United States seem to be more advanced in their understanding of ASD. For example, in places such as Hong Kong, there are no mandatory special education classes that teachers must complete in order to teach children with special needs, whether they teach at inclusive schools or special education schools (Ling, Mak, & Cheng, 2008). This also makes it difficult when families from countries outside of Canada and the United States and are not educated or informed on what ASD is and how the resources and treatment that is received in North America are different than what they may get in their home country. The stigma may still be there, but gradually over time, the stigmatization of ASD for both the individual and their family, will hopefully diminish as people in society become more educated about what ASD is and how it is different from other disabilities, especially physical disabilities.

Educators, professionals, and caregivers need to be on the same page in terms of the information given about ASD, the resources that are available, and how to be culturally and ethnically sensitive when encountering diverse families.

**Statement of the Problem**

Many families of diverse cultural and ethnic backgrounds do not know the benefits of an ASD diagnosis, may not know where to access many of the treatment choices that their children qualify for, may be unable to overcome the stigma of their child being labeled as ‘autistic’, and do not have accessible information about ASD in their own language. Another part of the
problem is that professionals who are working with families of children with ASD do not have the appropriate cultural or cultural sensitivity training to work with families from the vast amount of cultures and ethnicities in Canada. It is important that professionals are able to understand the beliefs of various cultures and ethnicities in order for them to be culturally and ethnically sensitive when speaking to families about their child with ASD. Being culturally and ethnically sensitive will allow professionals to be able to provide more extensive care and will hopefully allow parents to be more trusting and open with the process of getting their child designated and getting them access to the appropriate care and resources that are provided once their child is designated.

**Purpose of Project**

It can be very intimidating for parents that are not from Canada to be able to ask for help when English is not their first language. The purpose of this project would be to give parents access to information about ASD, where to access many of the treatment and resource options, the benefits of a diagnosis and getting this diagnosis early, all while having this information easily accessible to the parents in their own language.

**Overview of the Project**

This project will include a website and a pamphlet; the pamphlet that can be accessible in doctor’s offices, speech pathology clinics, and the like for easy access and a quick read for parents. Both the website and the pamphlet can be translated in the future.

It is important that both the website and pamphlet be translated in a variety of languages in order for parents of various cultures and ethnicities to understand everything about what ASD is, and know that they are not alone in the process of having their child designated. Knowing where to start when there is suspicion that their child may be on the spectrum can be very daunting for
any family, but especially for families that are not from the dominant culture and who may not speak English fluently. The website will be an important first step for families; it will allow them to have access to it in the comfort of their own home, written in the language that they are most familiar with, and allow them to read through the website at their own pace and to process the information at their own leisure without the feeling of being judged by anyone.
Chapter Two

Literature Review

Defining Autism

The term “autism”, also known as “autism spectrum disorder” or “ASD”, refers to a wide range and variation of unique challenges that are displayed by an individual with the disorder. ASD is referred to as a spectrum disorder because there is not a singular definition for autism; the challenges and strengths for each individual are unique and the conditions characterized by these individuals are displayed in a range (“Autism Speaks”, n.d.). ASD is a developmental disorder which can include impairments to an individual’s social interaction and communication, and can involve repetitive behaviours such as “hand flapping, smelling and mouthing objects, rocking and twirling and finger-gazing” (Mak & Kwok, 2010, p. 2045). ASD is unique to every individual, thus suggesting that there are various combinations of genetic and environmental influences that makes diagnosing ASD quite challenging. ASD can be diagnosed in individuals as early as 18 months, but children with ASD are said to display the most-obvious signs between the ages of two and three years old.

A topic that will be discussed further in this chapter is the issue of stereotypes when it comes to ASD. One of the main reasons individuals with ASD are stereotyped or stigmatized is because of the combination of their typical physical appearance and their disruptive and socially inappropriate behaviour. In the past, the general lack of knowledge surrounding ASD caused many people to stereotype and stigmatize individuals and families with ASD, but as more awareness surrounding this disorder becomes evident in society, especially in North America, the hope is that the amount of stigmatization towards individuals and families affected by ASD will decrease.
Autism Awareness or Epidemic?

Globally, there has been a steep increase in ASD diagnoses over the past two decades; this prevalence of ASD has been increasing at a steady rate around the world and is now being called an ‘autism epidemic’. It is estimated that 1 in 59 children have autism and the prevalence is four times more likely to occur in boys than in girls according to the Centers for Disease Control and Prevention (“Autism Spectrum Disorder (ASD)”, 2018). This prevalence is up 30% since 2008 and is more than double the prevalence of 1 in 150 in 2000 (Wright, 2017).

There may be many contributing factors to the increase in prevalence of ASD, but researchers have said that although it may seem like there is an ‘autism epidemic,’ it could be that medical practitioners, educators, parents and society as a whole have become more aware and knowledgeable about what ASD is and the early signs of ASD. Over the past two decades, our criteria of what ASD is and our awareness and knowledge surrounding ASD has increased substantially, and thus could be contributing to the rise in prevalence globally (Wright, 2017).

Although our awareness and knowledge has increased around the area of ASD, we still have a long way to go in terms of combating the stigma that is often attached to an ASD diagnosis. Combatting the ASD stigma will take time and increase in public education for those families that may not have someone in their life with ASD; it is important to be aware that there is a stigma around any diagnosis, including a diagnosis of autism spectrum disorder.

Defining Stigma

Stigma is defined by Goffman (1963) as “an attribute that is deeply discrediting” and reduces the individual “from a whole and usual person to a tainted, discounted one” (p. 3). After Goffman, stigma was discussed less as an attribute and more as a process with three components. In the first component, Link and Phelan (2001; 2006) say that people observe, identify and then
proceed to label differences in others, which leads into the second component: stereotyping. This second component of stereotyping means that people begin to assume and apply these assumptions indiscriminately to all of the individuals in the labeled group. After these stereotypical assumptions are applied, people start to avoid or distance themselves from people in this labeled group, which makes people in this labeled group feel even more different than they already are. As humans, we are full of emotions and members of the stigmatizing group may feel fear, annoyance, and/or disgust towards the stigmatized group, while the stigmatized group may feel belittlement, shame, and/or embarrassment from the stigmatized group. The final component to complete the stigma process is the action of people using these stereotypes, which results in acting on emotions to discriminate against these individuals in the stigmatized or labeled group. This can lead to denial of access to certain goods and services that may be offered to other people in society and/or exclusion altogether (Link & Phelan, 2001; 2006).

Stigma is something that is widespread across many areas and can cause significant implications towards the treatment of individuals with mental illness and special needs - more specifically, ASD. Both mental illness and ASD do not usually come with any physical manifestations, meaning that they are known as invisible disabilities. Individuals with ASD have a typical physical appearance but have disruptive, distinctive, and socially inappropriate behaviour, which is a breeding ground for stereotypes, especially from those who are not educated enough and have a general lack of knowledge about ASD (Kinnear, Link, Ballan & Fischbach, 2016). Many people in society do not know the turmoil that families face when they find out their child has ASD. Although there are many resources and interventions to help both the individual with ASD and the family, the stigmatization that comes with an ASD diagnosis is still an area that contributes to the overall challenge of raising a child with ASD in society today.
Stigma and ASD

When a child is diagnosed with ASD, the label brings with it a lot of unknown elements for the family. Every parent wants the best for their child and knowing that their child has been diagnosed with an invisible disability is worrisome due to the stigmatization that goes along with it. Questions of whether or not the child will be treated differently in life because of his or her abnormal behaviours but ‘normal’ physical appearance, whether or not they will be rejected or excluded while growing up, and whether or not their child will be stigmatized are all questions that run through the minds of parents when their child gets diagnosed with ASD. Stigmatization not only affects the child with ASD, it also predicts how difficult life will be in general for the parents and family of the child with ASD. It has been shown that the stigma that is associated with ASD is widespread and significant (Kinnear et al., 2016). There are various repercussions that occur due to the stigmatization of ASD and some of them include shame, guilt, social exclusion, self-stigma, and internalization of stigma, just to name a few.

The research surrounding ASD has become extensive over the years. ASD was first explained through a psychoanalytic lens and now has shifted to genetic and cognitive explanations, but the stigma and stereotypes surrounding the previous explanations of an ASD diagnosis still lingers to this day. These stereotypes have caused parents to experience something called courtesy stigma. Courtesy stigma can also be known as associative stigma, or a stigma of association, that is experienced by people, usually family members, that are connected to the stigmatized group (Kinnear et al., 2016). This courtesy stigma results in parents being unable to properly bond with their child, which causes a disconnect between both the parent and the child with ASD – the parents detach themselves from the relationship which causes a strain, all due to the child’s diagnosis (Kinnear et al., 2016). Due to the typical physical appearance and often disruptive and
socially inappropriate behaviour of an individual with ASD, there is a general assumption that go along with society’s lack of knowledge around ASD. Many people will place some sort of blame on the parents and/or family for not being able to control their child’s odd behaviours in public and this causes families of an individual with ASD to carry around a lot of shame and guilt (Kinnear et al., 2016). This shame and guilt could further exasperate the relationship between this child and their parents.

With regards to the child’s socially inappropriate behaviour, this along with the stereotypes placed upon them, can cause rejection to both the child and the family, which in turn causes feelings humiliation, exclusion, and isolation from family and friends. In a social setting for the child, many children with ASD are rejected from their peers at school and outside of school, which causes an increase in stress for the parents and family.

Families of an individual with ASD may experience what is known as affiliate stigma, also known as self-stigma and perceived stigma (Chan & Lam, 2018). Self-stigma is the awareness and acceptance of the negative implications that society has towards them and its incorporation on their own value systems, whereas perceived stigma is the awareness of society’s negative implications and evaluations toward themselves (Chan & Lam, 2018). Self-stigma is said to have “more detrimental impact on psychological well-being” (Chan & Lam, 2018, p. 45) due to the internalization of the stigma from society and the implication it has on one’s self. This can cause damage to one’s self esteem, negative self-thoughts, and thus causing a detrimental construct on parents of children with ASD (Chan & Lam, 2018). Parents that tend to internalize these stigmatizing thoughts brought on by society begin to automatically have more negative thoughts about themselves, which impacts their identities – they begin to believe and perceive themselves as inferior or incompetent to others and thus diminishing their sense of value and purpose in life.
These negative thoughts of one’s self can become automatic for parents of children with ASD and can be detrimental to their mental health; these thoughts diminish their self-efficacy and self-esteem which in the long run can cause an increase in negative mood, depression, and emotional distress (Chan & Lam, 2018). Many parents of children with ASD go through this process of stigmatization, but it seems that cultural stigma plays a significant role in parental response to an ASD diagnosis.

**Cultural Stigma and ASD**

In Canada, we are surrounded by an abundance of cultures and a variance of ethnic origins, which is why it is important for educators to be culturally sensitive when it comes to ASD and its diagnosis. In 2011, there were more than 200 reported ethnic origins, over three-quarters of Canada’s population reporting to have some religious affiliation, and less than one-quarter (23.9%) of Canada’s population claiming to have no religious affiliation (“Immigration and Ethnocultural Diversity in Canada”, 2018). The way that every culture handles disabilities of all sorts can be vastly different – this could be due to varying degrees of education and awareness about ASD, different sets of values, and/or varying degrees of sensitivity when it comes to facing a diagnosis like ASD (Chan & Lam, 2018).

It has been known that in Chinese cultures, there is a great emphasis on biological roots when it comes to disabilities, this meaning that many Chinese parents are actually blamed for their own child’s developmental disturbances because Chinese cultures believe that if someone is born with a disability it was due to the bad genes being passed down from the parents (Chan & Lam, 2018). Further, Chinese cultures also place an importance on interpersonal relationships and social identity, which causes many Chinese parents to be highly sensitive to the stigma put upon them by the public (Chan & Lam, 2018). Chinese cultures are very concerned about face loss and how
they are perceived in public to others, and when you have a child with ASD, the stigmatization and stereotypes will cause a cultural shame on the family as a whole that many other families mainly in North America will be unable to relate to. Some families in Hong Kong and Asia go as far as sending their child to live with relatives far away so that they do not have to endure the public stigma that may come with having a child with behavioural issues such as ASD (Chan & Lam, 2018). In Canada, we have had an influx of immigrants - in 2011, immigrants represented the highest proportion among the G8 countries, which was 20.6% of the total population (“Immigration and Ethnocultural Diversity in Canada”, 2018). With these staggering numbers, and the assumption that immigration rates will continue to increase over time, cultural sensitivity should be at the forefront when we are continuing to train educators.

In Canada, although it varies from province to province, many of the special education teachers are required to have a specific number of hours and/or courses on special education training. This is very different from the requirements in Hong Kong. “In Hong Kong, teachers are not required to obtain special education training prior to teaching children with special education needs in both inclusive and social schools. Special education courses are electives that teachers can opt to take voluntarily, with many of them constituting no more than 30 hours of training on basic knowledge of students with diverse special education needs” (Ling, Mak, & Cheng, 2008, p. 239). The lack of knowledge educators have in Hong Kong has been known to cause an increase in frustration and a lack of overall understanding of why children with ASD act the way they do. With more knowledge and more hours of working with children with ASD, educators showed an increase in patience, understanding, and coping strategies to deal with their abnormal behaviours, as well as, a decrease in wanting to punish the child (Ling, Mak, & Cheng, 2008). In knowing this, it should not be surprising that parents who emigrate here from countries
such as Hong Kong, do not have the same level of understanding about ASD as parents who are from North America. The lack of understanding, knowledge, and training that is required of the educators in Hong Kong is next to none, and thus the parents will not have much understanding of how to help their child succeed academically and socially like they would here in North America. It is important that educators and professionals in North America are able to relay an abundance of information in a culturally sensitive manner that is clear and concise and easy for the parents and family members to understand.
Chapter 3

Project Plan and Proposal

Introduction

This project is titled, “Understanding and Overcoming the Cultural and Ethnic Stigma of an Autism/ASD Diagnosis.” Canadians are incredibly proud of our multiculturalism and ethnic diversity, but this cultural and ethnic diversity comes with its downfalls. These downfalls include the problem of accessibility and lack of knowledge surrounding an ASD diagnosis for culturally and ethnically diverse families in Canada. Many families may not understand what an ASD diagnosis is and the benefits of an early diagnosis, they may not know where to go to access the many treatment options that their child is able to utilize once they do have an ASD diagnosis, but the main reason as to why this project is important is so culturally and ethnically diverse families are able to overcome the stigma of their child being labeled as ‘autistic’ and have access to a wealth of knowledge in their own language, in which they are able to read at their own leisure in the comfort of their own home without the feeling of outside judgment.

This project will be designed as a website and a pamphlet, to make it easily accessible to others including educators, families of individuals with ASD, and others; in it there will be information about what ASD is, the benefits of an early diagnosis, what types of treatments options there are, the benefits of treatment, the goals for the social and emotional wellbeing of the individual, and what the future for the family may look like. The website and pamphlet can be translated in the future, keeping in mind that the website and pamphlet are designed for the parents and families of individuals with ASD that may come from different cultural and ethnic backgrounds.
It can be very intimidating for parents that are not from Canada to ask for help when English is not their first language. The purpose of this project would be to give parents access to information about ASD, where to access many of the treatment and resource options, the benefits of a designation and getting this designation early, all while having this information easily accessible to the parents in their own language. This is why it is important that this website be translated in a variety of languages in order for parents of various cultures and ethnicities to understand everything about what ASD is, and know that they are not alone in the process of having their child designated. Many parents will notice that their child may be different from other children at school, but it is difficult to know where to start when parents have suspicion about their child possibly being on the spectrum. It is difficult for parents born in Canada to know where to start when it comes to an ASD diagnosis, for parents that do not speak English or who are not from here, this can be an incredibly daunting experience for parents and their families of a child who may be on the spectrum.

This project is a crucial first step for families of various cultural and ethnic backgrounds who may not speak English as their first language. This is a main step that is missing throughout the process of getting an individual an ASD designation early on in their life. It is important for families to develop a strong understanding of what ASD is and how they are able to help their child succeed in both their social and emotional wellbeing, and how they are able to help them thrive in an academic setting. The translation of the website will allow families to have access to all of the information about ASD in the comfort of their own home, written in the language that they are most familiar with, and allow them to read through information on the website at their own pace and to process the information at their own leisure without the feeling of being judged by anyone.
The Project Description: Purpose, Goals, and Knowledge Transfer

The information for this project will be presented in the form of a website and a pamphlet. I will create both the website and the pamphlet with the intended audience being the parents and families of individuals that may be on the autism spectrum or who are on the autism spectrum, that come from culturally or ethnically diverse backgrounds who may not have access to an abundance of information about what ASD is and the benefits of an ASD diagnosis. Research has shown that parents’ beliefs influence their behaviour and medical decisions when it comes to how they handle the medical choices for their child with ASD. Many studies have demonstrated that there is a general lack of information about ASD in non-Westernized countries and this may be contributing to the problem of failing to provide the appropriate treatment and support for these individuals. (Alqahtani, 2012). My vision for this project is to provide families of culturally and ethnically diverse minorities who may be impacted by ASD a place where they can access information about what ASD is and how they are able to get more information about ASD in their community.

The purpose of this project is to provide families of individuals with ASD with the most information that they will need in one place. For families of culturally and ethnically diverse backgrounds, coming to Canada and not speaking English as their first language can be quite challenging, and when families have an individual in their family that may be on the spectrum, the information surrounding ASD can somewhat be ‘lost in translation’ quite literally. Some families may not understand what ASD is, if they come from a country that doesn’t have an
abundance of access to research surrounding ASD; this leaves a gap, in which, this website will be able to fill.

The goal of this project is to contribute information about ASD to the culturally and ethnically diverse community that is so often missed in the area of special education. It is important that these families do not feel like they are going through this process alone, that there are people and resources to help them and their families overcome the stigma and challenges that may come with an ASD diagnosis.

The reason why this project is being presented electronically in the form on a website is to allow families to read the information on their own time and in the comfort of their own home. With technology being so widespread now, many families will be able to have access to the internet via a mobile device, laptop, or tablet. Access to information is crucial for early detection and possibly early intervention (Nwokolo, 2010). I think that with technology being so widespread now, creating a website was the most efficient way to create accessibility to the most amount of people in the shortest amount of time.

As mentioned in the previous chapter, there has been an influx in the number of Asian, mainly Chinese, immigrants that have come to Canada – this meaning that there is also an increase in the number of Chinese cultures in Canada. In Chinese cultures, a great emphasis is placed on biological roots when it comes to disabilities, this meaning that many Chinese parents are actually blamed for their own child’s developmental disturbances, including being diagnosed with ASD. It is believed that if someone is born with a disability it is due to the parents passing on ‘bad genes’ to their child; this idea tarnishes their interpersonal relationships and social identity, which causes an increase in stress due to the stigma that may be put on them by the public. This, in short, means that they lose face in society; their outward appearance in public is
tarnished and there is a sense of shame on the family due to an ASD diagnosis, or any developmental disturbance, for that matter. This is a notion that many families who are born in North America cannot relate to, which is why it is important to know about this sort of information in order to be culturally sensitive to these individuals. Chinese cultures are so concerned about the loss of face in public, presenting this project in the community did not seem like the most suitable way to relay the information to parents. In order to be culturally and ethnically sensitive, it is important to allow families to be comfortable when approaching the topic of ASD. The information can be a lot to take in and having a presentation in a room full of parents and strangers can be daunting and overwhelming, and in order to save face, it could be assumed that many families would not show up because they may feel ashamed or judged. When the project is presented in the form of a website it will allow the parents and families to have access to all the information surrounding the area of ASD, allowing them to read it on their own time, in the comfort of their own home, and reading it in the language they are most familiar with. The translation part of the website is something that will be addressed in the future but is so crucial for the success of this project for this audience.

**Support for the Project**

One of the main reasons for wanting to create this project is due to having worked in the field of special education as a behaviour interventionist and working directly with families who were not born in Canada and finding it frustrating having that lack of understanding between the parents and families and the educators. It has been a constant struggle with client’s families, having them knowing that there is something different with their child, but them not being willing to have their child referred for an assessment because they were afraid of their child having that label. The problem seems to be a language barrier, but it is also a cultural and ethnic
barrier. The hope for this project is to not only bring the information about ASD to the parents and families, but to also bring awareness and education to the teachers, educators and support staff, of these individuals that come from culturally and ethnically diverse backgrounds. It is not so much that they do not want to help their child, but they do not possess the background knowledge surrounding the ASD diagnosis because no one has explicitly explained it to them. In order for educators to help these individuals and families, there has to be a mutual understanding about the background of ASD and the cultural and ethnic background that these individuals come from, and we have to be willing to be culturally sensitive when approaching topics and issues such as an ASD diagnosis. In order for the individual to get the help and treatment that they need, the families must be on board, and this project is a good stepping stone to allow parents to understand ASD and the steps that need to be taken in order for their child to succeed socially, emotionally, and academically both inside and outside the classroom.

Potential Challenges

One of the main challenges of this project will be the constant updating of the research surrounding ASD. ASD is always evolving and we are finding more research to back up the data and treatment plans that we use to implement on individual’s behaviour plans, etc. The challenge being that with a website, it will be difficult to always stay up to date on the most updated research that is out in the public. To combat this challenge, there will have to be multiple updates to the website in the future. It is important to always stay up to date on the most recent research and informing parents and families about this sort of research will be displayed through the updated website in the future.

Another challenge for this project is providing the appropriate translation for the website. Some languages do not have the exact words to directly translate appropriately. In order to
combat this challenge, it is important to get the translation as close to, if not exactly, to a direct
translation as possible.

Conclusion

The hope for this project is to close the gap that between when the first signs of ASD are
evident, to when a child is referred for an assessment to determine whether or not they are on the
spectrum or not in culturally and ethnically diverse families. It is important for all families in
Canada, and around the world, to feel supported throughout the process of an ASD diagnosis.
They need to feel as if they are not alone; they need to understand what ASD is and that an ASD
diagnosis is not the end of the world. This project will allow them to read about ASD and the
resources and benefits that come with a designation in the comfort of their own home, in the
language they are most familiar with, without any stigmatization or judgement from outsiders.
Chapter Four: Reflection and Conclusion

Introduction

This chapter will discuss and reflect on the creation of my project, including the process of research on ASD, early signs of ASD, the benefits of early intervention, the stigma surrounding ASD, the cultural and ethnic stigma around ASD, and the available resources and programs for individuals with ASD. This project will be beneficial to parents of individuals with ASD, educators, and the general public. The presentation and the format of this project is something that I am proud of because of its easy accessibility and the layout of organization – a sort of “one-stop-shop” for the cultural and ethnic stigma surrounding individuals with ASD. As with anything, there are limitations within this project, one of the main limitations being the need for continued research. We know so much more about ASD than we did ten or twenty years ago, but there is a need for more research, especially around the topic of cultural and ethnic stigma towards individuals with autism and its long-term effects on these individuals. I believe that this website, and the research behind the website, will be beneficial for the field of special education because it will provide parents of individuals with ASD, educators, and others to access the current research on the topic along with resources and programs that can help guide them in the right direction thereafter.

Successes of the Project

I am proud of the many successes that come along with this project. The way that I decided to format and present the information had the sole purpose of the level of comfort for the target audience. The target audience for this project were mainly parents of individuals with ASD, along with educators, and others interested. The topic of cultural and ethnic stigma surrounding individuals with ASD carries with it a level of sensitivity that I had to be very mindful of when
choosing how to present the information at hand. Developing a website would allow the most updated information to be on the website, but it would also allow parents of individuals with ASD to access this information in the comfort of their own home. I think because the stigma surrounding ASD is evident in the research, especially for people of diverse cultural and ethnic backgrounds, being able to read up on information in the comfort of one’s own home was a top priority when thinking about how to present the information to the target audience. Realistically, due to the stigma surrounding ASD as well as, the cultural and ethnic stigma around ASD, doing a presentation through an informational session did not seem like the right fit for the main target audience of parents of individuals with ASD.

The website begins with providing the reader with background knowledge about what ASD is, some early signs of ASD, and the benefits of early intervention. The background knowledge gives the reader a foundation of information to allow them to become familiar with what ASD and how getting help early on can greatly benefit the individual with ASD. From there, the reader will read on about the stigma around individuals with ASD and what the differences is between ASD stigma and cultural and ethnic stigma. Stigma not only impacts the individual with ASD but it also has a severe impact on the lives of the family members of the individual with ASD as well.

My idea for this website was to create a safe space for parents and families of individuals with ASD. It is so easy to become overwhelmed with a possible diagnosis and one of the common feelings of families that have been told their child may be on the spectrum is denial. Allowing families to read through this website on their own, in the comfort of their own home, at their own place, is something that was very important to me when designing this project. Something that will also help with the level of comfort for the main target audience would be getting the website
translated into different languages in the future. That way when the reader is searching through the website in the comfort of their own home, on their own time, and at their own pace, they are also reading this culturally sensitive information in their own first language – a language that they are most familiar with and that they understand best.

This website does not encompass all the information on the topic of ASD or cultural and ethnic stigma of ASD, but it is a great stepping stone of information on the topic. I believe the topic of cultural and ethnic stigma of ASD is something that hasn’t been research very much, and providing a website with information on this topic will be beneficial not only to parents of individuals with ASD, but also for educators that work with individuals with ASD.

Limitations of the Project

The limitations of this project included lack of research surrounding the area of cultural and ethnic stigma of ASD. Although there is some research on the topic, there was a lack of research in North America about the impacts of cultural and ethnic stigma on individuals with ASD in Canada and the United States. Although this website provides a platform of information, there needs to be research on how cultural and ethnic stigma effects individuals with ASD in North America and the impacts on their behaviour, social skills, and overall development as they grow up. If this topic was a thesis, the research could indicate areas of need that educators need to be focused on as more individuals of culturally and ethnically diverse backgrounds come through our school system. There could be discussions, meetings, support groups, and ongoing research and feedback on the process and the way it has helped or hindered the lives of culturally and ethnically diverse families with individuals with ASD.

In order for us to truly understand the impacts of cultural and ethnic stigma on individuals with ASD, there needs to be more evidence based research and this is something that may
happen over the following years and decades as we get more information about ASD and its impacts on the lives of people in North America.

**Implications for What I Have Learned**

Designing this project and the process that has come with it has been enlightening for me. The area of cultural and ethnic stigma surrounding individuals with ASD is something that I have encountered throughout my career, and being able to combine my passion for helping individuals with ASD and their families through this website has been incredibly eye opening. Upon having an idea for this project, I had no idea what the research would show. I have worked with clients of a variety of cultures and ethnic backgrounds and knew there was something that we as educators were falling short on between how we relay information about ASD to the parents and families of individuals with ASD, and how we support them throughout the process of a designation and thereafter. Upon further research on the topic, it was evident very early on that the way individuals that fall under the umbrella of special education are treated in various countries outside of North America is very different than how they are treated and supported here. That is something that educators need to understand. The way educators handle a culturally sensitive situation can be portrayed differently due to our lack of knowledge and training for culturally and ethnically diverse backgrounds. The word denial came up in the research and that is something that families of individuals with ASD face when given a diagnosis. No one wants to hear that something is wrong with their child, but culturally and ethnically diverse families must know that although their child is labeled as being on the spectrum, there is an abundance of support through various resources and programs that will help them along the journey.

The way that every situation is handled will be unique to every family. I think providing educators with the proper training about cultural and ethnic sensitivity can be beneficial to many
people long-term. This website can provide a platform of education and training for educators around the topic of cultural and ethnic sensitivity when it comes to helping families of individuals with ASD. I think this is something that will be more evident as Canada becomes a more culturally and ethnically diverse community, and it is important that as educators, we are prepared to handle these situations to the best of our abilities with the proper training provided to us. This website can be used for a variety of purposes. It can be used as a professional development day for educators to bring awareness to the topic of cultural and ethnic stigma surrounding ASD, but it mainly will serve as a platform for families of individuals with autism that may have come to North America from a different country, may not speak English well, or for individuals in the community who would like to know more about the topic at hand.

**Conclusion**

Overall, this project was inspired by the many clients that I have worked with over the years. The process of an ASD diagnosis is difficult in itself for families, but the cultural and ethnic stigma that comes along with a diagnosis, with an added language barrier can be incredibly daunting for families to tackle themselves. It is our job as educators to provide these families with the support they need to understand the magnitude of a diagnosis, and provide them with the abundance of resources and programs that we are so fortunate to have here in North America. With all that being said, the research that exists in the field does have its gaps, I think that as educators it is important for us to stay on top of all the updated research and to be constantly willing to learn about what works best for culturally and ethnically diverse families and individuals with ASD. My hope is that the end product of this website and pamphlet will provide families of individuals with ASD, educators, and the greater community with more knowledge surrounding the topic and ideas for future steps to help in their community or school.
References


WHAT IS AUTISM?

Autism Spectrum Disorder, or autism, is a neurodevelopmental disorder that impairs both social development and communication abilities. It affects individuals to experience communication problems, difficulty with social interactions, and a tendency to repeat specific patterns of behavior.

Earlier screening and diagnosis results in earlier and, therefore, more effective treatment.

If minority groups do access services but then experience poor cultural sensitivity and awareness from service providers, they may reject these services. Services then lose the opportunity to engage with the community and boost understanding, and the risk of stigma remains.

FOR MORE INFORMATION ON UNDERSTANDING AND OVERCOMING THE CULTURAL AND ETHNIC STIGMA OF AN AUTISM DIAGNOSIS, VISIT: https://autismstigma.weebly.com

THE CULTURAL AND ETHNIC STIGMA OF AN AUTISM DIAGNOSIS

“Raising an autistic child is hard enough, let alone raising one in a culture in which the stigma surrounding autism still runs high.”
WHAT IS STIGMA?

- The term ‘stigma’ comes from the Greek word ‘stigma’ which means “a mark, dot, puncture.”
- When someone is “stigmatized” it means they have been marked or labeled as inferior and different (in a negative way).
- When the public stigmatizes people we call this ‘social stigma’ or ‘public stigma’.
- There is an abundance of evidence that individuals with autism (and their families) are stigmatized.

EARLY SIGNS OF AUTISM

(12 to 24 Months) – child may demonstrate only a few of these symptoms

- Begins to develop language then loses it, or doesn’t acquire language at all.
- May appear deaf, respond unevenly or not at all to sounds.
- Difficulty coping during transitions (tantrums).
- Difficulty sleeping/wakes at night.
- Does not “point and look.”
- Failure to bond (e.g., child is indifferent to parents’ presence).
- Self restricted/restricted diet.
- Limited imaginative play.
- Not interested in playing with other children.
- Chronic gastrointestinal problems.
- Repeated infections.

CONSEQUENCES OF STIGMA

- Stereotyped/repetitive behaviors (e.g., inattention, character weakness, dangerousness).
- Negative emotional reactions (e.g., fear, anger, pity).
- Discrimination (social exclusion, rejection, incivility, employment discrimination, hate-crime, mate-outing, negative professional responses).
- Poor mental health and well-being (e.g., depression, self-harm, loneliness, hopelessness).
- Self-stigma (i.e., believing and accepting the public stigma’s view). This can lead to worse mental health, concealment and the ‘why try’ effect.

POSSIBLE REASONS FOR CULTURAL AND ETHNIC STIGMA

- Knowledge about autism: possessing poor knowledge about a phenomenon increases the likelihood of stigma toward it.
- Service provision: knowledge is power in some cultures due to less service provision – in cultures and communities with less available & accessible quality service provision, higher rates of stigma will exist.
- Religion: there is strong evidence that higher levels of religious faith are linked with higher rates of stigma, part of the reason for this may be because higher religiosity leads to be found in communities where services are less available, inaccessible or distrusted.
- Health inequalities: increases the risk of lower understanding, knowledge and awareness which in turn increases the likelihood of stigma manifesting.
Appendix B

Website

Understanding and Overcoming the Cultural and Ethnic Stigma of an Autism Diagnosis

What is Autism?

The term "autism", also known as "autism spectrum disorder" or "ASD", refers to a wide range and variation of unique challenges that are displayed by an individual with the disorder. ASD is referred to as a spectrum disorder because there is not a singular definition for autism: the challenges and strengths for each individual are unique and the conditions characterized by these individuals are displayed in a range.

According to the DSM-IV-TR, the diagnostic features of ASD include impaired social interactions, impaired communication, as well as restricted, repetitive, and stereotyped behaviour patterns.

Benefits of Early Intervention

Studies have shown that early intervention is crucial for individuals with ASD. But stigma can prevent families of individuals with ASD from being diagnosed at an early age. The stigmas associated with diagnosis are different for every ethnicity and culture.
What is ASD?

ASD is a developmental disorder which can include impairments to an individual’s social interaction and communication, and can involve repetitive behaviours such as ‘hand flapping, smelling and mouthing objects, rocking and twirling and finger-gazing’ (Mak & Kwok, 2010, p. 2045). ASD is unique to every individual, thus suggesting that there are various combinations of genetic and environmental influences that makes diagnosing ASD quite challenging. ASD can be diagnosed in individuals as early as 18 months, but children with ASD are said to display the most-obvious signs between the ages of two and three years old.

ASD Awareness or Epidemic?

Globally, there has been a steep increase in ASD diagnoses over the past two decades: this prevalence of ASD has been increasing at a steady rate around the world and is now being called an ‘autism epidemic’.

There may be many contributing factors to the increase in prevalence of ASD, but researchers have said that although it may seem like there is an ‘autism epidemic’ it could be that medical practitioners, educators, parents and society as a whole have become more aware and knowledgeable about what ASD is and the early signs of ASD. Over the past two decades, our criteria of what ASD is and our awareness and knowledge surrounding ASD has increased substantially, and thus could be contributing to the rise in prevalence globally (Wright, 2017).
Early Signs of ASD

One of the most important things you can do as a parent or caregiver is to learn the early signs of autism and become familiar with the typical developmental milestones that your child should be reaching. Earlier screening and diagnosis results in earlier and, therefore, more effective treatment. Recognizing the early signs of autism can lead to optimal outcomes. Know what to look for.

The timing and severity of autism’s early signs vary widely. Some infants show hints in their first months. In others, symptoms become obvious as late as age 2 or 3. Every child is unique and not all children with autism show all the signs. Many children who don’t have autism show a few. That’s why professional evaluation is crucial.

The following are a list of “red flags” to be mindful of as your child grows up, these may indicate your child is at risk for an autism spectrum disorder. If your child exhibits any of the following, please don’t delay in asking your pediatrician or family doctor for an evaluation.
The Benefits of Early Diagnosis & Intervention

“We know that the best outcomes for children with ASD come from the earliest possible diagnosis and intervention”

-Dr. Kim and Dr. Koh from the Korea Institute for Children's Social Development

Early intervention for toddlers with ASD has been shown as being highly effective, with significant gains in IQ, communication and social interaction.

By starting as soon as the toddler is diagnosed, we hope to maximize the positive impact of the intervention.

Early intervention treatment services can greatly improve a child’s development. Early intervention services help children learn important skills including significant and positive changes in intelligence, language and daily living skills as well as motor and social skills. Services include therapy to help the child talk, walk, and interact with others.

The value of early intervention programs is well recognized. A focus on improving social support, parenting skills and parent-child interactions during early infancy has demonstrated gains that include the mental health of parents and children, less use of health services and long-term reductions in challenging behaviours.

Studies conducted have shown that within the first two years intensive pre-school intervention can accelerate developmental rates resulting in significant IQ gains, language gains and improved social behaviour.

Research indicates that for children experiencing a developmental delay, early intervention should commence as soon as possible. Even before a formal diagnosis has been made, very young children can benefit from interventions which focus on developing communication, language, interaction and play.
Due to the absence of conspicuous physical markers of ASD, when children with ASD display socially inappropriate behaviours in public (e.g., flapping, twirling, throwing tantrums, smelling and mouthing objects, engaging in self-destructive acts), they are often blamed for being willfully disobedient and disruptive.

**Stigma**

Stigma can be broadly viewed as the product of negativity towards a target group. This can take the form of:

- **negative attitudes** (e.g. authoritarianism, malevolence)
- **negative knowledge** (e.g. misconceptions, stereotypes)
- **negative behaviours** (e.g. discrimination, avoidance)

Stigma has a number of other guises such as *courtesy stigma* and *self-stigma*.

**The Impact of Stigma**

- The damage stigma causes is unnecessary, preventable, complex and extensive.
- Autism stigma impacts upon a wide range of psychosocial phenomena.

Autism related stigma is an issue that needs careful and urgent attention.
ASD affects individuals of all cultural and ethnic backgrounds; different cultural factors change how every individual experiences ASD due to varying interactions in their community, with their family, in their school, and with their health services. Cross-cultural research is needed to develop autism services that are culturally appropriate for regions where these services remain scarce.

The Problem: the services to support those with ASD and to educate the public about ASD are far from equally distributed around the globe.
Stigma harms not only children with ASD, it also harms their parents and their families. As with ASD, stigma targets anyone regardless of their culture or ethnicity, but cultural and ethnic minorities tend to be more severely affected by the impacts of stigma.

**Chinese Culture**

- public stigma refers to stereotypical beliefs and prejudicial attitudes endorsed by a sizeable group in society towards a discredited subgroup
- public stigma adversely affects children with ASD in different cultural contexts
- self-stigma may be culturally salient among Chinese parents of children with ASD
- Chinese culture emphasizes the biological roots of disabilities
  - many Chinese parents may be blamed for passing on bad genes that cause their children’s developmental disturbances
- Chinese culture places great importance on interpersonal relationships and social identities
- many Chinese parents may have a heightened sensitivity to the stigma endorsed by the public
  - once they are stigmatized by society, they may also internalize the stigma easily
- concerns for face loss may aggravate many Chinese parents’ experiences of self-stigma and perpetuate the adverse psychological effects
- many Chinese parents of children with ASD may be vulnerable to repetitive and habitual self-stigma
Under-Representation of ASD in Ethnic Minorities

"ASD is under-diagnosed and under-reported and that rigorous screening and comprehensive population studies may be necessary to produce accurate ASD prevalence estimates."

-Author Name - Chief Science Officer - Geraldine Dawson, Ph.D.

A comprehensive study on autism prevalence, the first of its kind, was done using a total population sample that estimated the prevalence of ASD in South Korea to be 2.64%, which results in approximately 1 in every 38 children. This is an increase from the 2018 report from the Centers for Disease Control and Prevention.

These results were shocking to experts and may change the way we approach identifying children with ASD. The study was done using about 55,000 children ages 7-12 years of age in a South Korean community. These children were assessed systematically using multiple clinical evaluations.

**ASD may be under-represented due to the lack of awareness and lack of knowledge.**
In many parts of the world, including some underdeveloped and developing societies, there seems to be increasing concern over the rise in cases of ASD.

The first school for children with autism opened in the city of Cape Town, and there are now about five such schools in South Africa.

In some countries, these concerns have resulted in efforts to enact laws mandating early diagnosis and intervention: the provision of free, appropriate services and education for children with autism; acceptance and inclusion of such children in mainstream or regular schools; and training of special education and regular teachers on best practices in meeting the goals of each child’s individualized education plan.

Beginning in the United States in the early 1940s and in South Africa in the mid-1960s, serious efforts have been made in many parts of the world to recognize autism as a disability in its own class and to address its many challenges in South Africa. This effort began when Dr. Vera Buhrmam became aware of the extent of the problem of autism in Cape Town in 1970.

Sadly, this is not the case in Nigeria and various other parts of the world that do not have appropriate access to information about ASD and thus, do not know how to assess and treat ASD.

**Nigeria**

- the situation in Nigeria seems to hark back to pre-1943 America, when children with autism were thought to be schizophrenic or mentally retarded, and when maternal deprivation and spiritual causation held sway as explanations for its cause
- in many parts of Nigeria today, particularly in rural areas, people with autism are thought to be possessed or evil
Cultural Sensitivity Tips

Research shows that non-white families or recent immigrant families can have a more difficult time getting developmental services, which often delays a proper diagnosis.

Why Should We Understand Cultural Backgrounds?

In interactions with individuals and families affected by autism, understanding cultural backgrounds and how they may affect behaviour and the ability to communicate can go a long way toward developing genuine and effective relationships.
Although ASDs range from *mildly* to *profoundly* disabling, a diagnosis of ASD is an important *turning point* in a long journey. There are many resources for families whose children have recently received a diagnosis, families that may think their child may have ASD, or for families that want more information on ASD.

*You are not alone in this process. There is help to support you, your child with ASD, and your family.*