

**ONLINE INFORMATION FOR CAREGIVERS OF
ADOLESCENTS WITH AUTISM**

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Online Information for Caregivers of Adolescents with Autism

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Research Question: When caregivers of adolescents on the autism spectrum search online for information related to caregiving for their child, what information is available?

Abstract

Many adolescents with autism live at home with their immediate family. Family members, usually the mother, are often the caregivers of these adolescents. These families are present in all levels of society. Many find their caregiving duties challenging, as there is no clear consensus on how to best support adolescents with autism. Also, many caregivers lack the knowledge, financial resources, and time to provide optimal support. These challenges are uniquely distinct from challenges that caregivers of adolescents without autism face, and due to this experience, this group has its own certain characteristics, such as stress, fatigue, and health issues. This group would benefit from support for both themselves and their adolescent. One way to support this group is by providing specific, accessible, and reliable information that is relevant to their situation. One of the most common ways of obtaining this information is online. This paper evaluates websites that caregivers of adolescents may use to find this information and examines the challenges of finding usable information from these websites. These challenges include sorting through a vast amount of semi relevant information, often presented in advanced language, in order to find something that can be potentially be of use.

Keywords: Autism, Services, Family, Caregiver, Adolescent, and Ontario

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Focus of this Project:

This project is focused on families who are caregivers, who have one or more high functioning (HFA) adolescent aged 14-21. The individual(s) with autism live at home and participate in mainstream schools and extra-curricular activities, likely with the help of immediate family and community services. In this context, this project addresses family caregiver(s) who have assumed the role of raising and supporting an adolescent(s) with autism.

Introduction:

When it comes to autism the focus within research as well as in society is often on the individual with autism. This project will focus on a closely related although unique group of individuals that exist in every level of society regardless of ethnicity or economic status: persons who are caregivers of individuals with autism; and more specifically caregivers of adolescents with autism. These caregivers are often the parents of the adolescent with autism. This group is often overlooked in society; simply due to fact that many members of this group are too overwhelmed with their caregiving duties to advocate for themselves and their struggles. For example, they are busy with the constant need to coordinate the different supports, therapies, and other groups their adolescent partakes in. Caregivers enroll their children in these activities with the hope that they will help their adolescent successfully integrate in society. Caregivers are also busy for an adolescent who has mind of their own and does not always cooperate with the parent. This is further combined with other typical challenges one's experiences in life, for example challenges experienced within one's place of employment. This group also has its own health issues that caregivers often neglect due to being overwhelmed with their caregiving duties. Due to these challenges this group needs support, and moreover they deserve to be recognized as a specific group that requires both public and academic attention.

Although the topic of my research is mainly focused on challenges of caregivers of adolescents with autism, it is important to exam my project through the more general lens of disability. Autism, as I will discuss in detail later in this paper, has its own distinctive characteristics, however, in research as well as in society, autism is often perceived and discussed not only as a unique matter but also as part of the much larger issue of disability. As

such, in order to understand the relationship between autism and society, it is necessary to discuss the relationship between disability and disabled individuals within society.

Individuals with disabilities such as autism have faced societal discrimination throughout recorded history. Until recently, the recorded history of individuals with disabilities did not exist. This is because individuals with disabilities and their issues were not considered important enough to be studied and documented, and individuals with disabilities themselves were denied the appropriate tools and knowledge in order to record their own history. Therefore, there was a misguided notion that individuals with disabilities do not have any history at all (Fleischer-Zames & Zames, 2001). Even the word disability itself is relatively new. In the 19th century the term idiot was widely used (Rose, 2017). Nielsen (2012) a Professor of History at the University of Toledo discusses that her research was one of the first attempts to document the history of disability in the United States. Neilson writes that when conducting this research, in order to find relevant information, she needed to use alternate search terms to disability such as blind or retardation (Nielsen, 2012). However, the notion of disability and the stigma associated with is as old as humanity itself. For many years it was treated as a personal tragedy, a fate or even punishment from god. Historically, society looked upon those with disabilities with pity and fear. Additionally, the belief was held that by not associating with those with disabilities, this will prevent “normal” people from having to share the same fate. In Western society during the 20th century, the general population attempted to disassociate itself from disabled individuals by treating them with cruelty, as though they were not human. Those with disabilities were kept away from the eye of general public. Sometimes those with physical deformities were put on display for the amusement of general public to emphasize the idea that they are not “normal”. Even American President Franklin D. Roosevelt; a successful individual with a disability, tried

to minimize the effects of disability at least publicly to ensure that public will accept him as one of them and that he would not be identified by his disability (Barnes & Mercer, 2003, Nielsen, 2012). As autism is a disability, individuals with autism are included in this and experienced discrimination throughout history and through to today. Therefore, it is important to include this historic prospective to deepen our understanding of the complex relationship between society and individuals with disabilities.

With time as well as developments in the medical field, disability began to be viewed as something that can be explained through medical means. As such, disability was able to be at least be partially treated or assisted. However, it was still viewed as a personal affliction. Society still dissociated itself from these individuals by putting them away in segregated institutions “for their own good” (Barnes & Mercer, 2003, p.3). An individual with a disability was still viewed as an unfortunate, inferior creature whose life is dictated by medical professions. Those with disabilities were viewed as a burden, without any ability to contribute to society. Furthermore, they were viewed as incapable of making any decisions for themselves (Barnes & Mercer, 2003).

Prior to the 1960's, there were some efforts to accommodate individuals with disability in society such as schools for the deaf. During World War two, for a brief time it appeared that western society was starting to accept individuals with disabilities as individuals who are valued and capable to be contributing members of society. During this time many countries in the western world were desperate for as many working hands as possible in an effort to win the war. As such, many oppressed individuals such as women, racial minorities, and the disabled who previously were considered unemployable became a valuable part of the workforce. However, after the war when men returned home, these individuals were required to leave the workforce and resume their previous roles as noncontributing and seemingly incapable members of society.

In the late 50's and early 60's, there was some efforts towards deinstitutionalization for individuals, although at that time society was still far from supportive and inclusive for individuals with disabilities. However, the notion that individuals with disabilities should not be treated as social outcasts and committed in institutions became more prominent. Certain institutions themselves made efforts to appear more dorm-like and less like a hospital (Fleischer-Zames & Zames, 2001).

In the late 1960s due to societal change, an increasing number of oppressed groups in society demanded equal rights. Disabled individuals fought to be viewed as capable of making their own decisions; but it took several years for academic research to shift from viewing disability as an individual and medical issue to viewing disability as product of society. However, this shift slowly happened. Disabled people, due to their common experience of discrimination, began to define themselves as “an oppressed minority” (Barnes & Mercer, 2003, p.10). The power of to decide the fate of individuals with disabilities slowly began to shift from medical professions to the individual. The notion of an individual with a disability being invisible and removed from society was replaced with idea that people with disability are a vital part of our society with the same right to equality. The view in society started to shift to acceptance of individuals with disabilities. This shift was not only in the perception of disabled individuals but was also reflected in legislation through the creation of rules that serve to integrate these with disabilities (Barnes & Mercer, 2003).

In past thirty years the social model of disability becomes more prevalent. This theory does not view the individual as a medical subject. It states that an individual with a disability is not disabled due to their medical condition, but because the way society treats them (Barnes & Mercer 2003). Individuals with disabilities currently hold an increasing amount of leadership

and advocacy roles in academia and in politics as well. Individuals with disabilities are not only viewed as capable of making their own decisions they are actually doing that by advocating their desires and needs not only in academia but in mainstream society as well. The current view is not that an individual with disability should not be kept away from the public but instead that everyone has the right to be a vital and integral part of society (Barnes & Mercer, 2003; Oliver 1996).

The social model can also be described as perceiving an individual with a disability holistically and not solely focused on their medical diagnosis (Mullins, TEDMED, 2009). All individuals, regardless of disability, need certain adaptations to be successful. For example, we all need roads to get from one place to another. This adaptation is never questioned, and it should be the same way for individuals with a disability who require certain accommodations or adaptations. The same way that society provides roads that service the needs of the commuters, society should provide services for any individual who may require it.

Oliver (2018) argues that this is a human right issue. He discusses that with regards to the social model, it is not an individual's diagnosis but society that disables an individual. This view allows for individual with disabilities to rethink their place in society as both personal and political. Oliver (Oliver, 2018) discusses that although the social model was first introduced to medical students in order to reshape their thinking about disabled people and their place in the society; it was quickly adopted by disabled people themselves. This model became the basis for demanding political change and enacting policies that see an individual with a disability as more than their diagnosis, but rather as an individual who has the right to fully participate in society. This model is not only valuable tool for developing policies and changing the way society views an individual with disability, it is also important on an individual basis as well. It is empowering

for an individual with a disability to know that the challenges they may face are not solely due to their medical diagnoses but rather because of societal attitudes and norms. This can ensure that individuals can demand equal rights not because it's the nice thing to do – but rather because it is what's right.

Oliver himself admits that this model doesn't take into account the personal experience of impairment which will continue to exist regardless of societal practices. Oliver addresses this, stating that the social model of disability is not intended to address all issues related to disability, but rather it is an important tool for understanding the connection between disability and society (Oliver, 2018). He discusses significant issues related to disability including “oppression, discrimination, inequality and poverty” (Oliver, 1990, p.2), and that an individual's disability is due to “society's failure to provide appropriate services and adequately ensure the needs of disabled people” (p.3). The following image provides examples of societal barriers that can disproportionately affect individuals with disabilities:



<https://elspethslayter.com/2017/01/17/an-easy-bridge-to-build-for-supporting-children-with-disabilities-in-russia-and-the-united-states>

Figure 1

Critics of this theory such as Shakespeare (Edwards, 2008), argue that the social model has analytical flaws and can also negatively affect disability research, as well as individuals with disabilities themselves. He points out that there are certain conditions that no matter how much support is given, the individual experience is so prevalent that it overshadows everything else. For example, for an individual with chronic pain the pain itself may prevent the individual from fully participating in society. Another group that can experience issues related to participation in society is those with severe intellectual disabilities. Due to their impairment, even with optimal support some individuals are unable to fully participate in society. In my opinion, this group

faces a further level of discrimination, as certain individuals are unable to communicate what supports they actually need.

Another issue with the social model of disability is that it can be interpreted to mean that some medical research is irrelevant and searching for cure is unwanted. For example, Shakespeare discusses the hostile reaction to Christopher Reeve's desire to be “cured” and walk again: “I know there's a cure coming” he said to the telegraph on Sep, 26, 2001 (Shelden, 2001). This statement was met with hostility from some disability rights group, who rightly suggests that there is nothing wrong with a person with an impairment, and object to any medical intervention. In my opinion, there isn't one answer; there shouldn't be a rigid dichotomy between medical advancement and the social model of disability. As Shakespeare states: “it is not medicine, but inappropriate medicalisation which is the root of the problem” (Shakespeare, 2008, p.11). I believe that medical research does have a role, but it should be just one part of the services that can provide support for individuals with disabilities. For example, it is up to a medical researcher to develop glasses that can assist individuals with their vision, and it is up to society to make sure that these glasses are available to anyone that needs it.

This paper incorporates social model of disability. I believe the best way to support an individual with autism is by accepting the notion that autism is not something wrong or abnormal, but rather a part of human diversity. In order achieve an optimal quality of life; an individual with autism needs to live in a society that is supportive of their needs. Similarly, to how newer buildings are supposed to accommodate individuals with physical disabilities by having accessibility ramps and grab bars in bathrooms, (although of course this is not always the case) similar adaptations need to be put in place individuals with autism. One means of through which this can occur is through education. From a young age, children should learn that diversity

exists in human behaviour, and that this diversity should be welcomed and celebrated, and not a cause for discrimination. Additionally, we need to ensure that individuals with autism are viewed as an integral and valued part of society, and moreover treated as such. As society becomes more familiar with individuals with autism, the hope is that this will result in decreased discrimination and increased acceptance.

Fuentes' writing discusses this notion with regards to individuals with autism:

Autism spectrum disorders: Ten tips to support me.

“1. I am not “autistic.” I am first, foremost, and always a person, a student, a child, and I have autism. Do not confuse me with my condition. And, please, do not use the term in a negative or inconsiderate way. I deserve to be respected.

2. I am an individual. Having autism does not make me the same as other people with autism. Make an effort to know me as an individual, to understand my strengths, my weaknesses, and me. Ask me—and my friends and my family, if I cannot reply— about my dreams.

3. I deserve services, just like all children. Services for me begin early. Autism is—or it will be, when recognized—a public health issue in many countries of the world. There are instruments to screen it. They should be applied in the framework of screening for other developmental disabilities. If you start soon, my life will be different! And remember that about one quarter of my siblings will have autism or other problems. Help them; they are an important part of my life.

4. I belong in the health care system, just like all children. Include me in regular health care. The health care system should adapt to me, limiting waiting times and ensuring that I understand what is to be done, by using, for example, easy-to-read materials, pictograms, technologic means, and so forth. Other patients also will benefit.

5. I belong with other children. Do not separate me from them because you want to treat me, educate me, or care for me. I can, and I should, be placed in regular schools and regular community settings, and special support should be provided to me in those places. I have something to teach other children and something to learn from them.

6. I belong with my family. Plan with me for my future and my transitions. I am the one who should decide, and, when my ability to do so is limited, my family and friends will speak for me. No government agency can take the place of my family, and, please, make sure that our society values my family's generosity when they support me on society's behalf.

7. I deserve the right to evidence-based services. These may not be convenient or easy, but when I get them, I do better. Do not substitute my educational, health, and social support with medication. I may require medication, and I look forward to new developments in biological treatments, but you must be cautious in their use. Count on me for research ventures; get me involved, with all my rights protected. I also want to help others.

8. I belong in society. Engage me in vocational training. I want to contribute. The services I need during my adult life should be guided by self-

determination, relationships, and inclusion in all the activities of my community.

Your goal must be to adapt the environment I have to face and modify settings and attitudes. It also will make our society better.

9. I have human rights, and I face discrimination for many reasons. Many of us live in poverty with no community support system. Some of us are immigrants or minorities, including sexual minorities. Keep a gender perspective. Girls and women with autism are often at greater risk of violence, injury, or abuse.

10. I belong in the world. I have a role to play. We, and my legal representatives, want to be involved in policy making, its development, and its evaluation. You need my help to know what should be done. Empower me. Remember my motto: nothing about me, without me.”

(Fuentes, 2014)

As discussed, some individuals with autism can have difficulty communicating what supports would be beneficial to them. Although this paper discusses mainly challenges related to caregivers of an adolescent with autism, it is important to note that in this case, caregivers can be a valuable source of information regarding what support the individual with autism could benefit from, as well as important advocates.

Oliver in his work often reflects his own experiences of disability. From reading his work and listening to him speak; he is clearly capable of advocating for himself and others in similar conditions. In contrast, some individuals with autism may be non-verbal or unable due to effectively communicate what kind of assistance they require and how society can assist them. As such, they may need someone to advocate on their behalf, and who better to do that

than those who are the closest to them, love them, and want them to succeed: their parents. As briefly discussed in Fuentes writing, in order to help individuals with disabilities such as autism, in the instances whereas an individual cannot efficiently advocate for themselves, more attention should be paid to the views of the caregiver (2014). Caregivers are the ones who provide daily support for the individual with a disability, and therefore are familiar with the challenges and daily experiences of the individual with a disability. Although the caregiver's views may not always be purely altruistic, they are the only ones who are most capable of understanding the needs and abilities of the individual with a disability. Through their advocacy, they can contribute to a more just society.

Another significant challenge associated with being a caregiver is that although society on one hand strives to include individuals with a disability; on other hand it also embraces the idea of neoliberalism: less government assistance and more personal responsibility (Mladenov, 2015). In other words: individuals with autism are expected to be integrated in society without proper support from the government, due to “expanding the market logic and principles (e.g., self-interest, calculability, competition, efficiency, profit) to all areas of life” (Mladenov, 2015, p. 3). Therefore, the theory of neoliberalism does not allow for the government to assist in supporting individuals with autism as it doesn't make immediate economic sense. As such, the family is responsible for providing the support that the individual requires and is expected to help their loved one integrate into society. Without proper government support, this is a difficult task. In many cases supporting an individual with autism it is not only a question of the economic aspect of neoliberalism, it is also another aspect of the neoliberalism philosophy: that the challenges associated with providing care for an individual with autism are viewed as a private and personal issue that is of little or no interest to others (Prince, 2012) . Moreover, as an

adolescent with autism in many cases needs support; this support becomes the sole responsibility of the family.

I believe that, due to the prevalence of neoliberalism in society, families of individuals with autism should be viewed as a marginalized group as well. Due to neoliberalism ideologies, they are the ones who provide care for the individual with autism, and as such many challenges that individuals with autism experience on some level the caregiver experiences as well. They also face their own challenges and may experience discrimination. For many caregivers, their duties affect every aspect of their life. These families may be unable to pursue the career of their choice, they may be unable to explore other interests, or plan any activity without taking into consideration their most important responsibility: supporting their family member with autism. This is not because of the disability of their child, but rather because current societal supports for individuals with autism are insufficient, and therefore it falls to the caregivers to provide any needed support. As such, I believe that caregivers of individuals with autism should be viewed as a marginalized group with their own distinct characteristics and identity. Furthermore, I believe that the social model of disability applies to them as well.

Due to this neoliberalism ideology that postulates less government assistance and more personal responsibility (Mladenov, 2015), the government to assist in supporting individuals with autism as it does not make immediate economic sense. As a result, there is insufficient societal support for an individual with autism. In many cases, the family is solely responsible for providing support to the adolescent, and for the integration of the adolescent in daily activities. They are also responsible for preparing them for the future when they will hopefully leave their parents home and live on their own, possibly with some support. The challenges that caregivers

of an adolescent with autism face cannot be fully be addressed in one paper, therefore this paper will only focus on one specific challenge that caregiver experience:

The need for reliable information pertaining to their caregiver's duties. As research on the subject of autism continues to expand and new services become available, families need objective, reliable information regarding whether these new services can be beneficial for their family.

Therefore, families of adolescents with autism need reliable sources of information for several reasons:

To know what information exists and to create a realistic plan for themselves and their adolescent: This would benefit families, as they could find information not only regarding their child, but for them as well, such as parent support groups.

To act as a reference point for reviewing their plans: Families of an adolescent with autism like any other families change with time and therefore their needs change as well. For example, their child may have previously enjoyed soccer, but now as an adolescent, their interests have changed. Reliable information on other inclusive physical activities would be beneficial for caregivers. From this, families could then reevaluate their next steps accordingly. One of the most obvious places to search for this information is on the World Wide Web. When searching for websites using my keywords, certain website that result do provide information that coincides with the medical model of disability. Although I personally disagree with this approach, it is still important to include in my paper, as many caregivers utilize these services for their children. Therefore, in my search results, I discuss whether the information from this websites is consistent with the medical or social model of disability. This is done in order to make clear the pervasiveness of the medical model within autism.

Searching for information online is seemingly straightforward; however, obtaining reliable and usable information online is far from simple. As such, this project will seek to accomplish two goals: First, creating a detailed profile of caregivers of adolescents on the autism spectrum and discussing their need for reliable and relevant information; then exploring when these caregivers search online for information related to caregiving for their child, what information is available? This paper will work to address this through firstly providing a background on the caregivers themselves, including their responsibilities and characteristics. It will then examine a specific need of these caregivers: the need for reliable and relevant information. This will be answered through a scoping review. This paper will next explore a method commonly used by caregivers to obtain this information: an online search. This paper will then discuss my research actually searching what information is available online for these caregivers. Following this, the websites found as a result of my search will be analyzed and critiqued, and common themes will be addressed. This paper will conclude with a discussion on how online information for caregivers can be improved as well as other related issues.

Research Paradigm

This project will utilize a mixed methods approach, using features from both quantitative and qualitative design. The research paradigms that will be used are a post-positivist approach as well as an emancipatory approach. It is post-positivist because my research is directly connected to my own experience. Even though much of the research is seemingly objective and quantitative in nature, the inspiration behind this project derives from my own personal experience searching online for caregiving resources. An emancipatory paradigm is also used, as I am a mother of an individual with a disability who requires my support. Therefore, I am member of this community as well. Being a member of this community provides me with a deeper understanding of my topic because this is an issue that I personally continue to face. However, as a researcher I still need to ensure that I remain objective and consider perspectives other than my own.

The motivation for this research is to improve circumstances for parents like myself within the community who provide care for an adolescent on the autism spectrum. Finding solid and reliable information online is a significant issue that caregivers face. Therefore, the purpose of describing this difficulty is so that it can be a steppingstone for changes that must occur in order to assist parents in overcoming this challenge.

Methodology

Terminology

I am purposely using terminology such as adolescent rather than youth because for the purpose of this paper, it is important to specify that I am discussing those of adolescent age, rather than young adults, which the term youth may imply. Although from my research it is evident that mothers are often the prime caregiver, the word caregiver rather than mother is also intentionally used throughout this paper. As will be discussed, in many cases caregivers experience feelings of loneliness and isolation. I do not want to add to these feelings by excluding others caregivers such as fathers, grandparents, siblings, who also can play a significant role in supporting an individual with autism. I do not want to add to this already feels unsupported and alone and dismissing all caregivers who are not mothers is adding to this notion of loneliness and despair. Additionally, to respect my son's privacy, I intentionally am not using his name when I refer to my personal experiences.

Data collection:

1. A scoping review to search existing academic literature pertaining to families who are caregivers of an adolescent on the autism spectrum. This will be done in order to create a general profile of the families who will benefit from this research. As autism is a lifelong disability, every stage in the life of an individual with autism has its own unique characteristics, and further presents different challenges for families. Families of an adolescent with autism significantly differ than families with young children or adults with autism disorder due to the unique

characteristics of adolescent with autism (Fong, Wilgosh, & Sobsey, 1993). Therefore, it is important to create a family profile that is specific to these families.

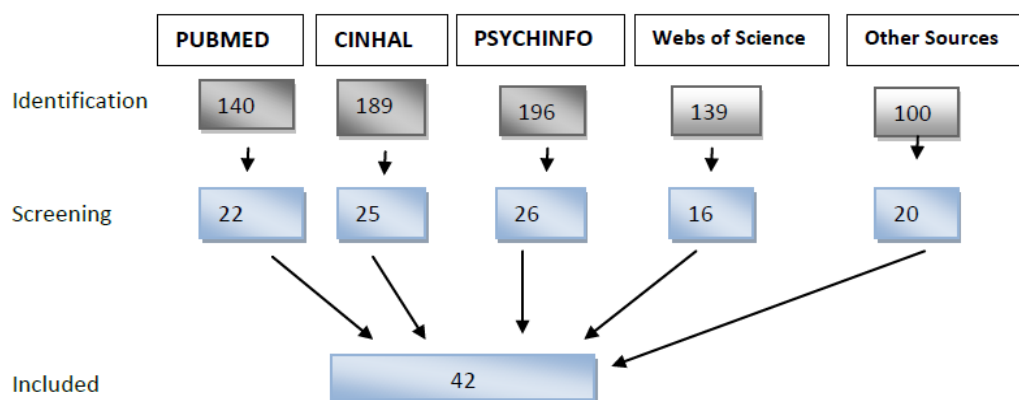
2. An overview of information that is available on the World Wide Web in Ontario in English using the following keywords: Autism, Services, Family, Caregiver, Adolescent, and Ontario.

Methods of Conducting Literature Scoping Review

Search Strategy:

I searched databases and reference sources such as PUBMED, CINHAI, PSYCHINFO and Webs of Science, using the following search ~~terms~~: Autism AND Adolescent AND (Family OR Caregiver). I also reviewed scholarly articles from my previous research that I have conducted in this area and added relevant sources. As my work progressed, I used statistics and additional articles that have been recommended by the Mendeley database and other scholarly sources including reference lists of articles that I read.

I have identified 764 articles, and after screening abstracts and searching for keywords in text the number of articles retained dropped to 109. After reading the full text the final number of articles included was 42.



Search Strategy Diagram

Figure 2

Methods for the Overview of World Wide Web Information

I reviewed websites that I can access from my home computer using Google in English using the following keywords: Autism, Services, Family, Caregiver, Adolescent, and Ontario. This was done to replicate the search a caregiver would do when searching for information on the World Wide Web. I included websites that are reliable according to Coates (2009) reliability criteria, and websites with a readability level that a typical caregiver can comprehend using the Automatic Readability Checker software. I excluded all websites that discuss information that is intended for professionals such as health care professionals and educators, and parents' forums. This criterion is further explained in detail below.

Exclusion criteria

I will not use:

1. Information that is intended for professionals such as health care professionals and educators. Caregivers or individuals with autism who are seeking information may have difficulty trying to understand this information since the language of many reliable sources is at a very high academic level. Information for professionals is often written above the twelfth grade level (see. Sabo, 2008, Web Sites by Flesh-Kincaid Grade Level P. 343)

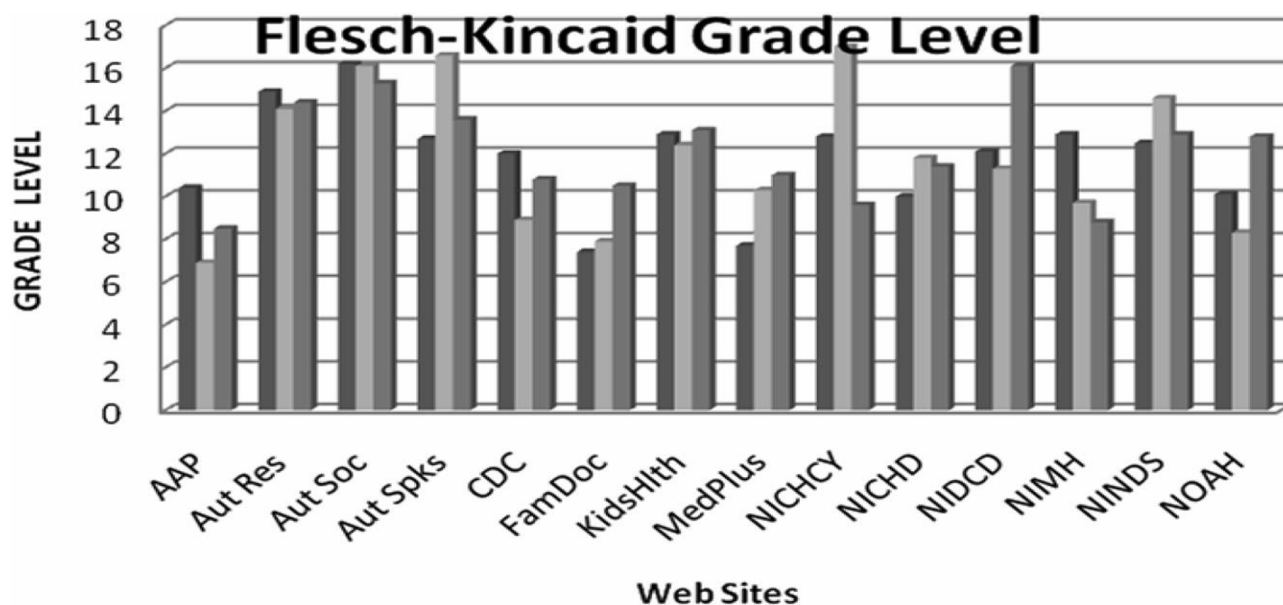


Figure 3

This is a significant issue for caregiver looking for information regarding autism online. This is because according to Sabo (2008), “the average American reads at the eighth grade level” (p.227). In Canada, “48 percent of adult Canadians have low literacy skills that fall below high school equivalency” (ABC Life Literacy Canada, 2018). Therefore, the literacy level required to comprehend this valuable information is often above the literacy level of the average parent.

This adds an extra layer of difficulty to the parent's struggle to obtain and understand important information. Additionally, immigrants who are substantial part of our society have additional language barriers due to English not being their first language (Sabo, & Lorenzen, 2008).

Therefore, they have further difficulty understanding this information. Another reason for not using this information is, since this information is not meant for caregivers, the usefulness of this information might be questionable, since most of caregivers lacking a professional background to fully grasp autism professional literature.

2. Parents' forums where parents exchange information among themselves. This information is meant to be private and not shared with non-members of these forums, and as such it is very hard to gather this information since it requires consent from many parents and from many forums. It also can be unethical since many parents are participating in such group is to find support (Huws et. al, 2001) and want to be free to express themselves without constraint of being a subject for academic project. Another reason for not using parent's forums as a source of reliable information is, the spread of false information that in some cases can be quite harmful. What is called in the media "fake news" (Peters, Tartari, Lotfinejad, Parneix, & Pittet, 2018). One of the studies (Mocanu, Rossi, Zhang, Karsai, & Quattrocioni, 2015) about Facebook, one of popular World Wide Web social platforms argue that information that exchanged there often are not backed by scientific evidence, and even sometimes contradict the scientific evidence present (e.g. vaccines – autism link). Therefore, I believe that parent' forums online are not immune to unreliable information due to parents being uninformed or even due to some other factors who want to spread unreliable information.

Inclusion criteria

In order to identify information as reliable I will use Coates (2009) criteria:

“A significant portion of the information provided is based on scientific research” (p. 261).

As previously discussed, there is a significant amount of information online regarding caregiving for these individuals that comes from ambiguous sources. It is extremely important to ensure that the information provided is based on reputable research.

“Does not advocate or propose a “cure” ” (p. 261). Autism is not disease that needs to be cured. It is a disability that needs to be accommodated, and with right accommodations the individual with autism can live a full and productive life.

“Does not advocate expensive treatments or treatments that may cause harm” (p. 261).

There are treatments (better termed supports) available that do not intend to “cure” but alleviate some difficulties that an individual with autism may face. One example is effective communication. An individual with autism may not express their needs and wants in a way that others can easily comprehend. This may result in significant miscommunication which can contribute to anxiety and frustration for the individual and the caregiver as well. A support that caregivers may seek out is Speech-Language therapy, which can teach an individual with autism and their caregiver alternative methods of communications such as picture exchange communication, sign language etc. In many cases, this is for a fee. Although it is reasonable to pay for a treatment, it is unreasonable to ask a parent to sacrifice their financial future in order to fund a treatment. The definition of harm can be quite subjective: when a treatment is not right for a specific individual and a result of it there was a waste of money and time is this called harm? If because of that other better treatment was not done then it can be a quite harmful for an individual with autism.

“Does not advocate one treatment for all individuals on the spectrum” (p. 261). Since autism is a spectrum disorder, there is no one answer for all individuals.

“Recognition of the individuality of presentation of the disorder across people and growth throughout the lifespan” (p. 261). As discussed previously, an individual with autism changes over time, and as such the needs of the individual and their family is also constantly changing.

It is important to restate that autism is not a disease that needs to be cured. The word treatment in my inclusion criteria can be misleading as it appears to imply that I am in support of the medical model of disability. Nevertheless, from my research caregivers are searching for information about available treatments, and as such I cannot dismiss that it is a significant information need. Coates (2009) uses the word treatment while strongly opposing that autism is something that needs to be cured. As such, a better term would be supports, however; treatment is the term that both Coates (2009) and caregivers are using, perhaps due to the dominance of the medical model in current disability rhetoric. I hope this term falls out of favour as the social model continues to gain acceptance in society.

I also will choose information that can be comprehended by a typical caregiver by using Automatic Readability Checker software which combined some of the most used readability formula:

“1. The Flesch Reading Ease formula will output a number from 0 to 100 - a higher score indicates easier reading. An average document has a Flesch Reading Ease score between 6 - 70. As a rule of thumb, scores of 90-100 can be understood by an average 5th grader. 8th and 9th grade students can understand

documents with a score of 60-70; and college graduates can understand documents with a score of 0-30.

2. The Flesch-Kincaid Grade Level outputs a U.S. school grade level; this indicates the average student in that grade level can read the text. For example, a score of 7.4 indicates that the text is understood by an average student in 7th grade.

3. The Fog Scale (Gunning FOG Formula) is similar to the Flesch scale in that it compares syllables and sentence lengths. A Fog score of 5 is readable, 10 is hard, 15 is difficult, and 20 is very difficult. Based on its name, 'Foggy' words are words that contain 3 or more syllables.

4. The SMOG Index outputs a U.S. school grade level; this indicates the average student in that grade level can read the text. For example, a score of 7.4 indicates that the text is understood by an average student in 7th grade.

5. The Coleman-Liau Index relies on characters instead of syllables per word and sentence length. This formula will output a grade. For example, 10.6 mean your text is appropriate for a 10-11th grade high school student.

6. Automated Readability Index outputs a number which approximates the grade level needed to comprehend the text. For example, if the ARI outputs the number 3, it means students in 3rd grade (ages 8-9 yrs. old) should be able to comprehend the text.

7. Linsear Write Formula is a readability formula for English text, originally developed for the United States Air Force to help them calculate the readability of their technical manuals. Linsear Write Formula is specifically designed to

calculate the United States grade level of a text sample based on sentence length and the number words used that have three or more syllables.”

Source : www.readabilityformulas.com/free-readability-formula-tests.php

Many of these formulas are widely used and been around for many years for example: Gunning FOG Formula developed in 1952 (Hansberry, et al., 2014). This formula used not only in academic writhing but also in other sectors such as American navy which commission conversion of Flesch Reading Ease formula to Flesch-Kincaid Grade Level formula mainly for assessing levels of technical manuals. By using the this method (formula that measures the level of readability in the English language), I disregard all websites with a readability score above the grade ten English level, however due to scarcity of websites meeting this criteria, I instead excluded websites above the grade eleven level.

Literature Review

Autism: What is it?

Autism spectrum disorder (ASD) is defined as a life-long neurodevelopmental syndrome that affects the way in which an individual communicates and relates to other individuals and the world around them (Lord, Cook, Leventhal, & Amaral, 2000). Most individuals who are diagnosed with autism remain somewhere on the spectrum and need some degree of support throughout their life (Ho, 2016). As autism is a spectrum disorder, there exists a wide range of symptom with different levels of severity. These symptoms may increase or decrease in severity during the lifetime of the individual with autism (Laghi et al., 2018), and as such every individual with autism requires an individualized plan of support that needs to be continuously revised and adjusted (Nicholas et al., 2015). Although extensive research has been conducted regarding autism, much about the disorder remains unknown. Therefore, there is no one consensus on what causes autism, and further what is the best way to support and individual with autism. As such, in many cases it is up to the caregiver (usually the mother) to decide what steps to take in order to accommodate individual with autism; regardless of the caregiver's knowledge and abilities (Adams, 2016).

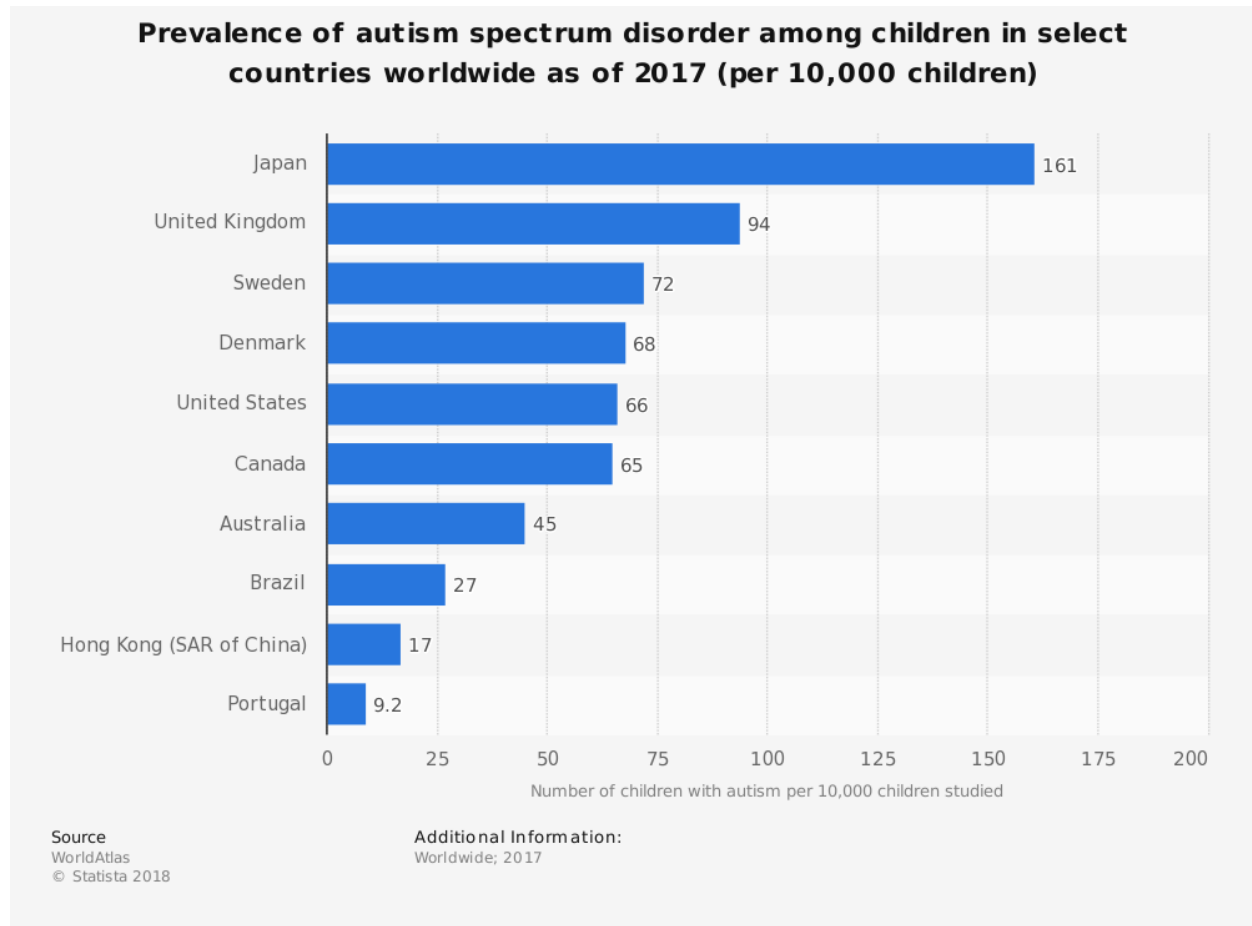
Although it was once thought to be true that autism is more common in affluent families, this is not the case. Autism is “evenly distributed across all educational and socioeconomic levels” (D'angelo, 2011, p. 4). Autism affects 36-60 individuals out of every 10, 000. It is described as a long life disability, and 80% of individuals with autism rely on their families and support services all their lives. Additionally, many individuals with autism have a “secondary or comorbid disorder” (D'angelo, 2011, p.3). Due to the limited research in this area, it is unknown

if treatments and services, that parents choose for their child is due to their autism or the secondary or comorbid disorders (D'angelo, 2011). However, it is known that individuals with autism access many therapies and services, even more so “than families of children with other emotional, developmental, or behavioral problems” (Vanegas & Abdelrahim, 2016, p.315). In fact, according to research by D'angelo (2011),

“families reported using a wide array of services, with an average of four different types of services outside of the education system. Common services included health services (e.g., hospital-based), speech and language therapy, respite care (i.e., babysitter service), social skills therapy, and behaviour intervention” (p.14).

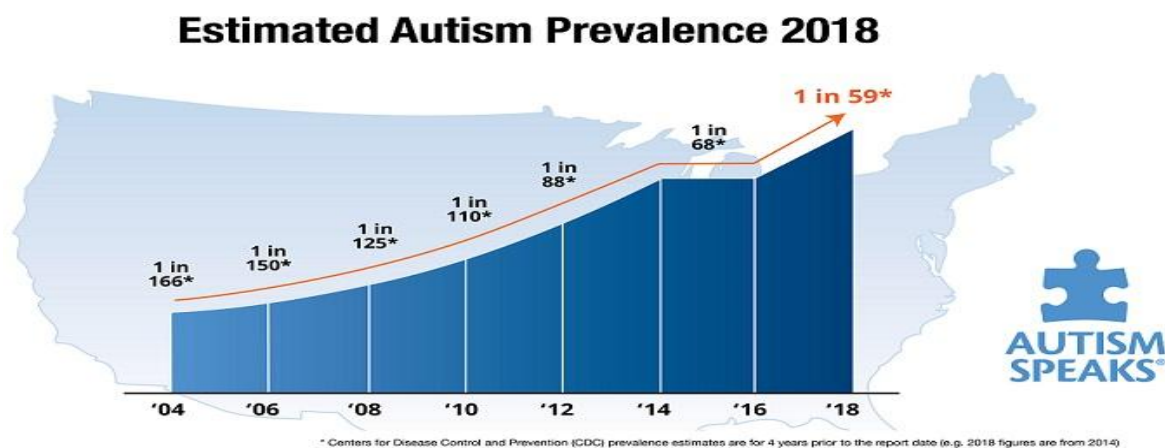
My son was diagnosed with autism over ten years ago, and I still don't fully understand it. What I mostly understand is what it is not, for example: “autism is not a mental illness, a mental health condition or a learning disability” (O'Grady, 2015, para 8). Common mantras that parents often hear from health professionals and educator's regarding their child's autism include: “your child is unique”, “you know him better than anyone else” and “you know what is best for him”. Statements such as these put the onus on myself to make all the decisions for my son, regardless of whether I know if they will be beneficial or not. There is no set “recipe” on how to build on the strengths of an individual with autism and do what is best for them, and unfortunately parents often fall short on providing optimal support for their child with autism to live up to their full potential (Adams, 2016).

Autism in Numbers:



(Statista. 2018)

Figure 4



(Autism Speaks Inc., 2018)

Figure 5

According to the Center for Disease Control and Prevention (CDC), there is a 15 % increase in the prevalence of autism nationally: to 1 in 59 children, from 1 in 68 two years previously.

According to Gerhardt & Lainer (2011): “70% of the currently identified individuals with ASD are less than 14-years old” (p.37). This means that today (2020), there is a growing group of families who have an adolescent(s) with autism. This group is large and important enough to be recognized and researched as group on its own in sociological and disability studies.

My Personal Experience Caring for an Adolescent with Autism

My son was diagnosed with autism over ten years ago, at the age of three and a half. Currently he is attending a mainstream high school in a special class for students with autism. Although I assume most of students in this class indeed have autism, the teachers in this class are educated on disability in general, which means that their expertise on adolescents with autism is possibly limited. His teachers are convinced that despite him being very bright; his autism

prevents him from succeeding academically. In his school there are two programs that are intended for students who cannot succeed academically: hospitality (cooking and meal preparation) and mechanics. My son like many individuals with autism is very fidgety and regularly stims. Due to this reason, for safety reasons his school does not want him to use any tools such as knives or screwdrivers. This decision effectively closes the opportunity of his school to assist him in obtaining a profession within these areas and be a contributing member of society. My son is a bright young man, who without proper support is unfortunately destined to survive off welfare. Unfortunately, his school whose mandate is to educate students and prepare them for life is failing to do so with my son (and other adolescents with autism) (Weiss, Wingsiong, & Lunskey, 2014). As such, it is up to me to find a way for him to find his niche and live an optimal life.

Despite being connected with many professionals with autism over many years, I have no clear idea of what to do next and what path to take. Most of the information I have obtained regarding adolescents with autism are anecdotal and sporadic from reading, searching online and other parents in my situation. Most of my caregiving tasks are aimed on surviving and hoping the day will pass without my son being bullied, without receiving complaints from teachers (who should know how to deal with an adolescent with autism) or even phone calls from police and child services. I am as a caregiver who would benefit greatly from easy to understand and reliable information about all the aspects of caring for an adolescent with autism and caring for my family which is affected by my son's autism as well.

Role of the Family

Primarily due to advancements in the societal acceptance of individuals with disabilities, an increasing number of these individuals live at home with their families and are an integral part of society. Whereas previously, many individuals with disabilities were kept away and institutionalized (Barnes & Mercer, 2003). Due to this societal shift, families rather than professionals (such as doctors, therapists etc.) play the main caregiving role for their family member with a disability. As a result, these families have considerable influence on their dependant's lives. As stated by Weiss et al. (2014) "parents usually have the major obligation of caring for their child (which includes management of problematic behaviors) and balancing associated stress while overseeing the well-being of the rest of their family" (p.985).

Even though individuals with disabilities are no longer institutionalized, many still require significant support. Regardless of their readiness, it is often the immediate family who provides this support. As such, the families' life is also very much shaped by their family member with a disability as well. This can include changes in family dynamics, and planning for the future (Benzies, Trute, & Worthington, 2013). Currently, there is significant research regarding families who are caregivers for an individual with a disability. However, most of these studies focus on families with young children with a disability (Boyce, Miller, White, & Godfrey, 1994) despite the fact that many disabilities are lifelong and require some level continual support (Grossman & Webb, 2016).

Bourke-Taylor, Cotter, & Stephan (2015) discuss the importance of family centered practice, which "necessitates recognizing the family as central to decision-making about their child's needs and service access" (p.312). According to Mason & Pavia (2006), "family

typically forms the closest social unit outside the individual. Families buffer their members from outside society” (p.1, 010). Therefore, families hold a significant influence over the individual with a disability. In many cases, the individual with a disability relies on their family for many aspects of their daily life such as transportation to different appointments, arranging necessary therapies, meeting with schools, etc. (Vanegas & Abdelrahim, 2016). This influence of caregivers on the individual is more predominant when the individual is very young, or when the type of disability itself results in the individual being significantly more dependent on care. This decision making influence is usually expected from parents of any young children, however, in case of a child with a disability it may become a lifelong commitment (Grossman, & Webb, 2016), and as such significantly impact the entire family for a very long time.

Autism and Adolescence

Adolescence is a complicated period in life, partially due to the changes one experiences as they approach and reach puberty (Ho, 2016). During adolescence, an individual goes through a considerable change mentally, physically and socially. Physical changes, in combination with the transition to high school and an increased independence make this a significant stage of life for every individual. Due to these changes, even adolescents without autism usually experience some degree of difficulty during adolescence. Lack of appropriate support for an adolescent with autism can contribute to issues developing during adolescence such as “conduct disorder, drug misuse, anxiety disorder, mood disorders, depression, self-harm, eating disorders, and psychosis” (Larner, 2016, p.439). These changes are often hard and stressful on all individuals; however, in the case of an adolescent with autism these changes are exasperated due to the additional challenges of autism (Ho, 2016). Many adolescents without autism feel stressed, lonely, and as

though they don't belong (Van Dulmen & Goossens, 2013). These feelings of inadequacy are much harder in case of an adolescent with autism. For example, some researchers indicate a connection between intellectual functioning to higher levels of depression for an adolescent with autism. This might be due to the painful realization to the fact that there are different than others (Ho, 2016; Randeberg, et al., 2005).

In some cases obsessions, aggressive and destructive behaviours associated with autism become more predominant during adolescence. This is not to say that these behaviours were not evident previously, but they become more of an issue during this time period (Bagatell, 2016). For example, when a young child has a meltdown in public it is more socially acceptable, and can often be restrained if necessary. In the case of similar behaviour from a bigger and stronger adolescent, things can escalate mainly due to the disproportionate reaction from the social environment. Reaction such as principal telling the parent "there is no place for your son in my school" (Ho, 2016, p.23), or in some case authorities such as police or child services can become involved (Petalas, Hastings, Nash, Reilly & Dowey, 2012; Weiss et al., 2014).

Within the social model of disability, biomedical processes such as puberty still exist. Disability scholars have discussed that within the social model, it is important to discuss the body and the body should not be dismissed (Hughes & Paterson, 1997; Shakespeare, 2008). I am still very much applying a social lens, but it needs to be taken into consideration how an adolescent with autism might uniquely experience this time period, as puberty is a hallmark of the adolescence. Therefore, it is clear that due to the intersection of changes during adolescence as well as autism, without proper societal support, families of an adolescent with autism experience an additional set of challenges, on top of other challenges that they already experience.

Families of Adolescents with Autism

It is quite challenging to find specific characteristics of these families for several reasons:

Much of the research on families who are caregivers use “convenience samples” (Burke, et al., 2016, p.276), meaning mostly white (Burke, et al., 2016) families with a steady income and therefore those who can afford to take the time to participate in such studies. Families who’s time is occupied with caring for the adolescent with autism and the needs of other family members as well as providing for their family rarely have time to take part in meaningful research. As a result, many families with differing background are not represented accurately in the research despite that fact autism exist in diverse populations. Although some research fails to accurately represent the population, as several of these studies are qualitative in nature, the experiences of families who do part can provide insight on the broader population who struggle with the same or similar issues.

There are very few articles that concentrate specifically on adolescents with autism. Most of the articles view this group as part of the larger group of children with autism, for example in: *Caregiver Choice in Autism Intervention : Selections and Influential Factors* (Adams, 2016); or grouped with adults, for example in the article: *Diversity in Ontario’s Youth and Adults with Autism Spectrum Disorders: Complex Needs in Unprepared Systems* (Stoddart, et al., 2013). They are rarely addressed as one specific group. Interestingly, the notion that that research regarding families who act as caregivers of individuals with autism is mainly focused on young children is addressed in articles that are focused on older individuals with autism. As such, due to the insufficient research about this specific group of families, the information about this specific

group is quite limited (Bagatell, 2016). Moreover, according to O'Brien, (2016) this information does not exist.

Another reason for the difficulty in describing this specific group is that as autism is a continuum, many of the characteristics of families of young children with autism do not disappear once their child reaches adolescence. Many issues that families deal with during the early childhood of an individual with autism and the influence of these issues on caregivers continue during adolescence (Ho, 2016). However, years of constant caregiving can create a cumulative effect on the family (Weiss, et al., 2014). For example, a family who takes out loans in an effort to support their child gets deeper and deeper in debt as their child ages or due to continuous stress over time caregivers may develop mental health issues (Barker, et al., 2011). Therefore, much of the research about families with younger children is important and relevant to families with adolescents as well.

As discussed previously, adolescence can be a hard time in the life of any individual, and therefore has a significant impact on caregivers as well. Even an adolescent without autism can be uncooperative, hostile and even violent toward his/her family during this time period. These behaviours from an adolescent with autism can be challenging even for professionals who are supposed to help parents, and as such many families are left without adequate strategies on how to deal with these behaviours (Larner, 2016). Many adolescents with autism demonstrate aggressive and self-injurious behaviours. These behaviours are even more difficult for their parents to manage due to the adolescents' increasing physical size and strength (Ho, 2016). In addition to all the challenges of caregiving duties, safety issues can exist due to the "emerging sexuality" (Ho, 2016, p.5) of the adolescent with autism. Sexual urges combined with a limited understanding of social norms due to autism can cause the adolescent to "engage in risky sexual

behaviour or be a victim of sexual harassment or abuse” (Ho, 2016, p.5). Therefore, families of adolescents with autism face a set of challenges unique from other caregivers that which shape their distinct characteristics.

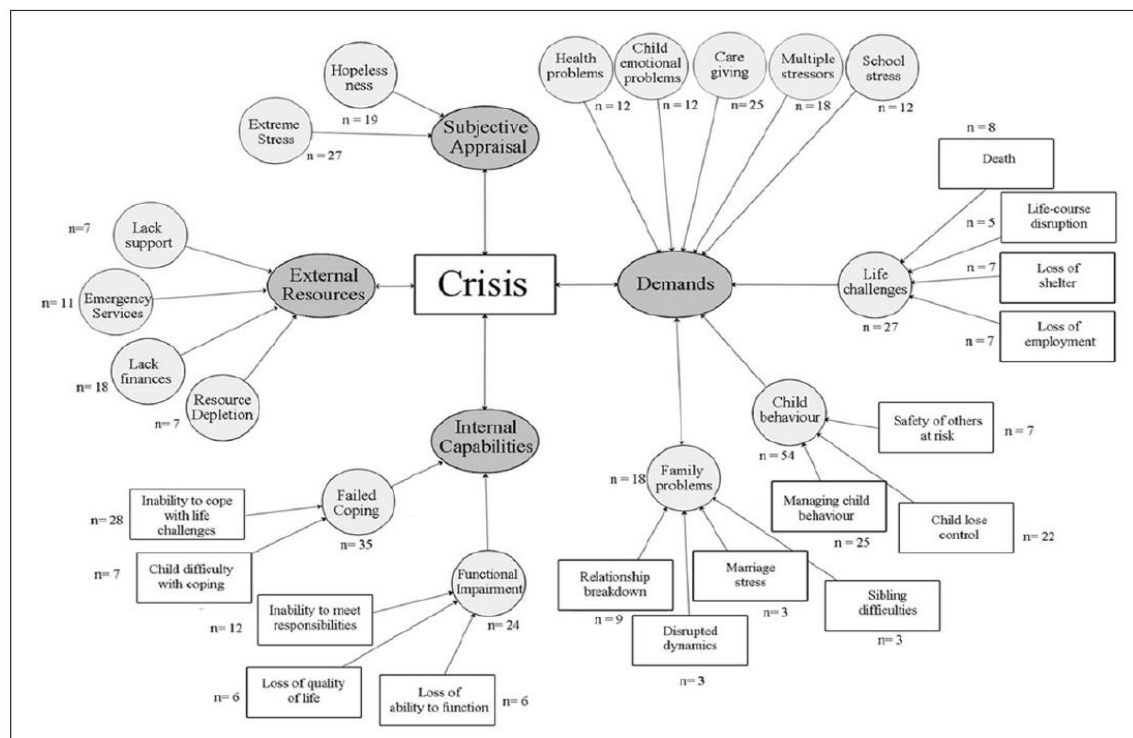
Responsibilities of Families who are Caregivers for Adolescents with Autism

In this section, the unique duties and responsibilities of families who are caregivers for an adolescent with autism will be discussed. Although many of these responsibilities continue from before adolescence, when a child become an adolescent many duties that caregivers previously faced became more challenging, and moreover new responsibilities emerge. These challenges are discussed in order to demonstrate that families who are caregivers of an adolescent with autism need assistance not only in their caregiving duties, but in every aspect of their complicated life in order to live a more healthy and productive life (Gerhardt, & Lainer, 2011; Stoddart et al., 2013).

Families of an adolescent with autism deal with all aspects of caregiving including the behavioural, emotional and health aspects of autism, in addition to the everyday challenges that all caregivers face. During adolescence, as in early childhood, caregivers need to be an advocate on behalf of their child. They must deal with all aspects of schooling and teachers, physicians and other health care professionals. They additionally are responsible for the variety of different services and ever growing number of prescriptions that an adolescent may take (Ho, 2016). Many of these responsibilities can be hard on a families and in some cases are beyond the family's capability. They might benefit from help by professionals, however, many times there is no adequate professional help and it is the up to the family to struggle with all the aspects of their caregiving duties (Larson, 2010). These duties can cause a crisis in the family due to “emerging

in the family system when the nature and/or number of demands exceed the existing capabilities of the family” (Weiss, et al., 2014, p. 985); and as such serve as a threat to the family cohesion itself (Mitchell, Szczerepa, & Hauser-Cram, 2016).

The following table illustrates the challenges that mothers of children with autism face:



Source: Weiss, et al., 2014

Figure 6

Although this research is based on relatively small numbers of families, most of the themes that this research represents repeatedly appear in different research regarding families who are caregivers for an adolescent with autism.

Additionally, there is a need to “manage” the adolescent themselves, who has mind of their own and may not always agree with their parents wishes. For example, it is much easier to take a young child to doctor’s appointment or give him/her medicine. Adolescents can refuse to

corporate with their parents well intended wishes, despite their caregivers' best efforts. My son refuses to take any medication, because he has read about the side effects of medications. Myself and his teachers have tried to explain to him that it will help him to concentrate at school. He remains firm in his decision, and I respect this. I cannot make this decision for him, as I may have been able to when he was younger. Making decisions for our children is more acceptable when they are younger. Many times, the level of cooperation between the caregiver and adolescent is dependent on the quality of their relationship. This relationship usually improves in early adolescence but deteriorates as the individual matures (Ho, 2016). However, even in my case where I have a strong relationship with my son, I cannot and will not coerce him to do things that he doesn't want to. This can be difficult as I know my son is the age where he can make his own decisions; although as a mother there are instances where I feel that I know what is best for him, such as studying before a test instead of playing video games. However, as with all individuals during adolescence, they sometimes do not consider the long-term implications of their decisions, in this example, being unprepared for a test.

Individuals with autism access a large number of therapies and services, even more so “than families of children with other emotional, developmental, or behavioral problems” (Vanegas & Abdelrahim, 2016, p.315). As such, “families reported using a wide array of services, with an average of four different types of services outside of the education system. Common services included health services (e.g., hospital-based), speech and language therapy, respite care (i.e., babysitter service), social skills therapy, and behaviour intervention” (D'angelo, 2011, p.14). Because of this, many times caregiving duties can be likened to a full time job, one that does not become easier during adolescence. Mothers of adolescents with autism spent an average of five hours of a day providing care, in comparison to mothers of adolescents who do

not have autism who spent three hours a day on average (Burke, et al., 2016). Families of adolescents with autism in comparison to families with adolescents who do not have autism are spend more time on less desired childcare duties such as helping with homework, which leaves less time for other more other more favorable interactions with the adolescent. The need for constant attention and supervision of their adolescent's activities are not limited to certain hours of the day, they continue even during times when parents can usually take a break (Larson, 2010). For example, when my "typical" daughters were adolescents, they spent a lot of time outside of the home with their friends doing activities that did not require my continual supervision. For my son, however, does not leave the house unsupervised. Moreover, continuous caregiving duties cause these families to have less "outings, vacations, and other activities" (Bagatell, 2016, p.50) that which "typical" families often enjoy.

Certain challenges for a caregiver of an individual autism become more pronounced during adolescence due to increased caregiving challenges. Parents, especially mothers report "more fatigue, arguments, and stressful events" (Burke, et al., 2016, p. 264) during this time. Moreover, from my personal experience of caring for an individual with autism, during the school year I received numerous phone calls from school with demands to pick up my son with autism from school due to autism related behaviour. This occurred despite him receiving education in a specialized autism class with trained teachers. This need to constantly be attentive to the adolescent with autism can negatively affect the ability of the parent to work and provide for the family, as their attention and time is focused on the adolescent as opposed to their workplace duties (Ho, 2016).

Moreover, as much autistic behaviour can stray from people's perception of "typical" behaviour, when out in public, families can be exposed to "hostile stares, insensitive comments

and blatant exclusion” (Broady, Stoyles, & Morse, 2017, p.2). As such, in addition to their usual caregiving duties, caregivers need to protect their loved one from the ignorance of others, and they too experience judgment and stigma, even from extended family and friends (Broady, et al., 2017). As stated previously, many behaviours that are more accepted by society when the child is younger are viewed much more negatively during adolescence. My own extended family has subjected my son and me to insensitive comments and moreover has excluded us at times. As such it is clear that the dealing with the stigma that is prevalent in current society also contributes to caregiving responsibilities.

Another significant difference between caring for a young child and an adolescent is the cumulative effect of caregiving duties. From my anecdotal experience it is around age 3.5 that we received a diagnosis, however, according to Pisula (2003) a child is traditionally diagnosed with autism around the age of 5-6, and presently The American Academy of Pediatrics recommends a diagnosis be made at 18 months. Despite the discrepancies in the age of diagnosis, caregivers have at least a decade of duties related to autism by the time an individual has researched adolescence. At the time of diagnoses as well as during childhood, caregivers have not yet experienced years of “Living and Breathing ASD” (Nicholas, et al., 2015, p.926). These years can include dealing with different organizations, professionals, treatments that are not always effective as well as a reduction in income. Years of this can result in a decreased amount of energy and motivation to seek out to new and different resources that may or may not improve their circumstances (Lake, Milovanov, Sawyer, & Lunsy, 2015; Weiss, et al., 2014).

Additionally, an adolescent with autism has a significant impact not only on the main caregiver but also on the whole family. This can include changes in the family dynamic such as less “mommy time” for other children, “reducing time spent with the typically developing

sibling, other family members, or responsibilities” (Phelps, et al., 2009, p30), financial difficulties and difficulty taking family vacations. It can also affect the “mood” of the family. This is because when the main caregiver is overwhelmed, stressed, and tired it can influence other family members including spouses, siblings and even grandmothers who may feel stressed and overwhelmed as well (Laghi, et al., 2018; Mitchell, et al., 2016; Sullivan, Winograd, Verkuilen, & Fish, 2012).

As evident from this section, families of an adolescent with autism have numerous caregiving responsibilities, in addition those that are experienced by families. It is not my intention to imply that these responsibilities are beyond the capability of every family who is a caregiver of an adolescent with autism; however, in order to demonstrate that these families need more support than they current receive, I deliberately chose to highlight the difficulties that these families face.

Characteristics of the Caregiver of an Adolescent with Autism

As result of their unique experience, caregivers of an adolescent with autism exhibit unique traits as well.

Much of research emphasizes that in many cases it is the *mother* that acts as the main caregiver for the adolescent (Bagatell, 2016; Dykens, Fisher, Taylor, Lambert, & Miodrag, 2014; Mason, 2012; Seymour, Wood, Giallo, & Jellett, 2013), though caring for an adolescent with autism has an impact on the family as a whole (Laghi, et al., 2018). Since the mother is traditionally the caregiver, she is the one who experiences most of the caregiving challenges, in addition to her other responsibilities. As such, she is the one whose life is most shaped by her responsibilities.

One of the most common features of the caregiver that is mentioned almost in almost all of the research is *stress*. This stress can arise from the constant needs associated with caring for an adolescent with autism, from dealing with organizations that are supposed to help; and additionally from an unknown and possibly bleak future (Bagatell, 2016; Ho, 2016). In addition to stress and also as a result of it, these caregivers can experience an elevated level of “*pessimism and depressive symptoms*” (Ho, 2016, p.5) even more so than caregivers of adolescents with other disabilities such as Down syndrome. Although in many cases the mother is the main caregiver, stress can affect all family members; even those who are not always directly involved with everyday caregiving duties (Mitchell, et al., 2016). Some caregivers experience feelings of *guilt*, and *blame themselves* or are *blamed by others* for their child’s autism (Mason, 2012; Nicholas, et al., 2015). These pessimistic thought of “shame, guilt, resentment and embarrassment” (Broady, et al., 2017, p.226) also contribute to general unhappiness.

Another common trait for many caregivers is being *chronically tired*. As one caregiver describes: “we’re all emotionally tired. We’re all physically tired” (Larson, 2010, p.20). As discussed in the previous section, being a caregiver for several years requires a lot of physical and mental strength, factors that contribute to general feelings of fatigue. Additionally, many caregivers do not sleep well due to their stress and worries (Smith, Seltzer, & Greenberg, 2012). Constant fatigue can create a vicious cycle when tiredness contributes to a reduced capability to cope, health issues and feelings of frustration, and these feelings reduce the capability for a good sleep and therefore add even more fatigue to an already tired caregiver.

Another characteristic of caregiver is that in many cases he (or mainly she) experiences feelings of *loneliness* due to isolation, and also due to the higher rate of divorce (Hartley, et al., 2010). Loneliness, stress, pessimism and fatigue combined with the daily duties of caring for an individual with autism for many years of caregiving contribute in many cases to higher levels of *depression, anxiety, and mental health-related issues* (Smith, et al., 2012; Weiss, et al., 2014). They are also physically sicker than the general population; they have “higher proportion of days with headaches, backaches, muscle soreness, fatigue, and hot flashes than mothers of children without disabilities” (Smith, et al., 2012, p.1836). One of the researchers found that caregivers are *aging much faster* “a decade or more faster than caregivers of typical adolescents” (Larson, 2010, p.16).

As described in this section, caregivers tend to be: mothers, stressed, and tired. Lengthy caregiving duties contribute to poor physical and mental health of caregivers; self neglect; neglect of attending other needs of the family and other family members; lower social economic status; higher divorce rate; and isolation. These characteristics create a very dismal picture of caregiver and do not represent the full picture of a caregiver’s experience. There is joy and

satisfaction in raising an adolescent with autism as well (Laghi et al., 2018; Seymour, et al., 2013); however, in order to make clear that these families need assistance in order to live an optimal life, I deliberately chose to concentrate on the negative aspects of caregiving.

The Need for Information by Families of Adolescents with Autism

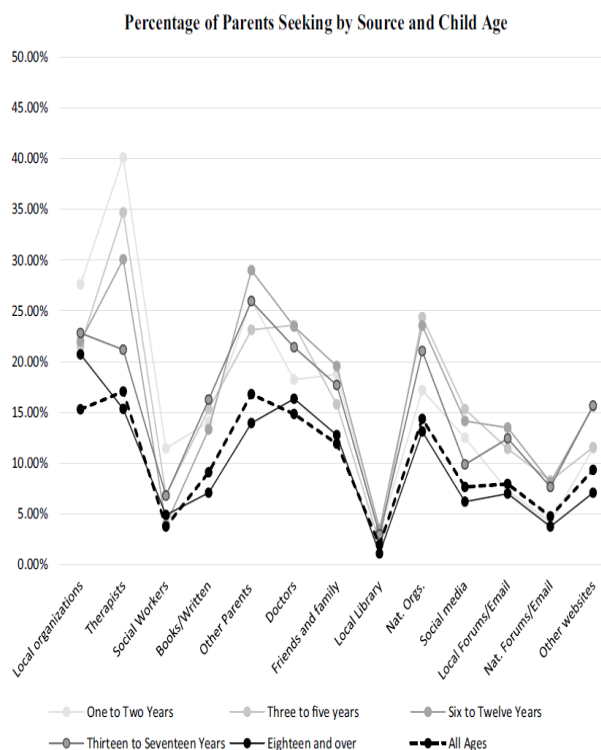
From the previous section, it is clear that many families of adolescents with autism need help. Many challenges are not adequately addressed by organizations that are supposed to help, leaving families to struggle on their own (Larson, 2010). Many families desperately need information that will help them to cope with these challenges. Information is needed on treatments, programs, services and other autism related issues. An online survey was conducted in 2008 at the University of Miami/Nova Southeastern University CARD of approximately 200 families of adolescents and adults with autism. The results showed that “67% of families surveyed had no knowledge of available transition programs and settings; 83% relied on family members as their primary source of transition planning assistance; and 78% were unfamiliar with agencies or professionals that might assist in job development” (Gerhardt, & Lainer, 2011, p.38). As evident from this research, even when services do exist, families are not taking full advantage of it due to being uninformed. In my opinion, one of the main reasons for this is that the information about these services is not communicated properly to the intended target in a way that families can comprehend. Therefore, I hope to prove that caregivers desperately need to have a means of obtaining information regarding the optimal way to help their adolescents with autism, and themselves as well.

As evident from the characteristics' of families of adolescents with autism, families will greatly benefit from any reliable information about any aspect of their complicated life. A survey of parents indicates that having information that will help them to find an appropriate support is a top concern for the parents (Brown, 2010). Most those families can benefit from reliable information for several reasons:

1. To know what information exists and to create a realistic plan for themselves and their adolescent. This would benefit families, as they could find information not only regarding their child, but for them as well, such as parent support groups.
2. To act as a reference point for reviewing their plans. Families of an adolescent with autism like any other families change with time and therefore their needs change as well. As such, it would be beneficial for them to revisit this information, while considering what worked well for them and what did not. From this, families would then reevaluate their next steps accordingly.

Parents do seek this information as best as they can (Huws, Jones, & Ingledew, 2001). The following table shows the sources that families uses in an effort to retrieve information:

Fig. 3 Percentage of parent seeking by source and child age



Source: Gibson, Kaplan, & Vardell, 2017)

Figure 7.

Families of adolescents with autism often feel frustrated due to the multisource of services. Parents must deal with many different people and agencies in order to get the help that they need and deserve. They sometimes feel lost and do not know what to do next. One parent states that: “it’s like trying to run through a maze blind folded” (Moodie-Dyer, Joyce, Anderson-Butcher, & Hoffman, 2014, p. 355). When families attend support groups where information is exchanged, they receive only anecdotal information, as they receive only limited information that other parents can share. Many parents lack time, must travel and experience childcare difficulties which can make it difficult to obtain support in the traditional way; from family and friends. Family and friends have difficulty in providing support because they feel that it can sometimes be more than they can handle, and further makes them feel vulnerable to the negative

aspects of life (Huws, Jones, & Ingledew, 2001). Therefore, it is beneficial for the families to use the World Wide Web to the information that they require.

Experiences of Families of Adolescents with Autism who Seek information Online

There exists some research regarding the experiences of families with a child with autism searching for information online (Reinke, & Solheim, 2015) however and I did not find any study specifically about the experiences of families with an adolescent with autism. From the research that I reviewed I found that families with children of all ages and abilities are obtaining information on the World Wide Web. In the United States in 2002, parents were online more than nonparents (more than 70% vs. 53%) (Doty & Dworkin, 2014). Families who are caregivers of an individual with autism have many additional reasons to look for information online. It is much easier to access information about autism online, due to the large amount of information that is available. Using the World Wide Web gives families the opportunity to make informed decisions about how to best take care for their children and not only leave the decision making to experts (Reinke & Solheim, 2015). However, the use of the World Wide Web greatly varies from families depending on household income, the education of the caregiver, and the age of caregiver and individual with autism. Age of the caregiver and the age of the person with autism are directly linked with the usage of World Wide Web for social support, as older caregivers are not using the World Wide Web as a resource for social support as frequently when compared to younger caregivers (Twombly, Holtz, & Daub-Sychra, 2011).

Obtaining reliable information for parents of an adolescent with autism on World Wide Web is not an easy task. There exists an “inherent paradox in the increasing availability of information, as families want to be kept informed but find that sheer volume of information

challenging” (O’Reilly, Karim, & Lester, 2015, p.512). Parents prefer information sources that can be catered to their specific needs. However, information on the web is very complicated and parents who are looking for information may have difficulty to access the precise information that they require. As described in Reinke, & Solheim, 2015 endless efforts of searching for adequate information about autism, can be a quite frustrating process.

Despite the challenges in retrieving satisfactory information on the web, the benefits of “having instant access to information” (Reinke & Solheim, 2015, p. 2371) any time anywhere without appointments or relying on professionals offset these challenges. The web gives families a “source of empowerment” (Reinke & Solheim, 2015, p. 2368), and allows caregivers to become more informed and a better advocate for their child. As one of the mothers in Reinke & Solheim’s (2015) research described: “...If I had not had the World Wide Web to actively seek out information and gain some comfort and feel like I was an active participant in those choices, I could not have done it” (p. 2368).

The following table provides of summary of the studies done recently on the use of the World Wide Web by parents seeking information regarding the health conditions of their children.

Author	Location/Setting	Internet Used for Medical Information Percent (Number)
Aslam et al. (2005)	United Kingdom; outpatient orthopedic clinics	18% (N=32/177)
Baraff et al. (2003)	United States; university pediatric faculty practice	46% (N=473/1018)
Boston et al. (2005)	United States; outpatient otolaryngology department	41% (N=83/204)
D'Alessandro et al. (2004)	United States; university pediatric clinic	68% (N=134/197)
Goldman and Macpherson (2006)	Canada; emergency department	56% (N=535/950)
Kind et al. (2005)	United States; neighborhood health centers	52% (N=136/260)
Massin et al. (2006)	Belgium; outpatient cardiac clinic	22% (N=84/389)
Semere et al. (2003)	United States; outpatient surgery clinic	63% (N=94/150)
Sim et al. (2007)	United Kingdom; surgical outpatient clinic	53% (N=144/271)
Wainstein et al. (2006)	Australia; children's hospital	64% (N=189/294)

(Sabo, & Lorenzen, 2008, p.39)

Table 1

As evident from this table, caregivers are actively using the World Wide Web in an effort to find resources and information to help them to cope with their situation.

Discussion

Although caregivers of an adolescent with autism fall under the much larger group of caregivers of individuals with autism (across the lifespan), as evident from the literature this caregiving group has their own specific characteristics. These characteristics differ from these of caregivers of individuals with autism at different ages. The limited published articles that view this group as a unique group were published quite recently. Although this is a positive step forward, the lack of current research on this group is troubling because this group deserves have be recognized in their own right and not only grouped together with all caregivers of individuals with autism. Additionally, there is limited research about the specific needs of caregivers of an adolescent with autism, and there is even less research regarding what sort of information these caregivers need. I believe this to be a significant omission. There are a large number of caregivers of adolescents with autism and therefore there are numerous people who if asked can articulate the challenges they face and what their needs are.

I believe one possible reason for the limited research in this area is that this group is easy to ignore. Young children with autism are receive significantly more attention in published research than adolescents (Stevenson, & Gernsbacher, 2011; Stoddart,et al., 2013) . This is possibly due to the fact that caregivers of young children with autism are new to the autism world as such have more energy and are more motivated to seek out and demand resources; they are not as jaded as caregivers of adolescents because they have not yet experienced the impact of several years of not receiving adequate support. This can possibly be attributed to neoliberal approaches that do not invest in necessary government services for them and their children. Moreover, as opposed to adults, adolescents often live at home with their parents, and therefore are less dependent on the government for their care. Parents generally provide support for their

adolescent with autism, and as such the government is not held responsible for the well being of adolescent with autism and their families. However, I strongly believe they should be and that too much pressure is being put on parents, as it is clear from this research that they need further support. Many of these caregivers have very little time for themselves and to attend to their personal issues, for example they may neglect their own health needs. It is documented in the research that caregivers of adolescents with autism have poor health due to putting their child's needs before their own. My doctor continually emphasizes that if I do not take care of myself I will not be able to take care of my child, who will need my support for many years. This notion was not addressed in the articles that I reviewed. I believe that many caregivers are unaware that by not attending to their needs as well as their child's, they themselves are not reaching their full potential and as a result are not providing optimal care to their loved ones. Published research highlights that caregivers seek out information that mainly pertains to their caregiving duties. However, I did not find published research that demonstrates that caregivers search for resources on how to improve their own lives. I believe the lack of published research further demonstrates that caregivers continually neglect their own personal needs.

Having reliable information pertaining to both caring for adolescents with autism as well as caring for oneself is extremely important. From the literature that I reviewed, it is clear that caregivers are searching for information pertaining caregiving from variety of different sources. Caregivers need appropriate and reliable information about providing for an adolescent with autism such as: the steps that need to take to improve their life and life of their loved ones, and what are services available. Without this information, it is difficult to create a meaningful and practical plan for the future. For example, a caregiver may decide that it would be beneficial for their adolescent to attend a high school that emphasizes integration. Without adequate

information regarding these schools, this plan will never materialize. As such, I strongly believe that having a reliable, clear, and easy to comprehend information is particularly necessary in order to provide optimal care for an adolescent with autism.

The World Wide Web can be an extremely beneficial tool in seeking out the information that caregiver desperately need. Despite the challenges in retrieving satisfactory information on the web, the benefits of the World Wide Web seem to offset these challenges. The web gives power to the family, because they can access information that is available about their specific needs directly. However, the World Wide Web is only a form of technology, only a tool. It is not a perfect tool, but it can vastly improve quality of life for families. Therefore, there is a definitely a need for more research in this area. Additionally, most of my reviewed articles indicate that there is an unmet gap between information that families need, and information that families currently have. Unfortunately, most of the articles that I reviewed mainly discuss challenges and suggesting more research in these areas without offering concrete solutions to this issue.

World Wide Web Search

World Wide Web Search Background

Numerous websites provide information regarding autism (Reichow et al., 2012): several with solid information and unfortunately various that are useless or even harmful such as misinformation, fake news, and information that isn't evidenced-based (see Methods for the Overview of World Wide Web Information section for inclusion and exclusion criteria). Yet, due to the fact that there are a plethora of different websites without any specific system or order it is extremely difficult to sort through the numerous websites in order to find reliable and relevant information. For example, research that reviewed 145 websites regarding autism revealed that "80% of the websites had information that could not be verified as accurate" (Reichow et. al, 2012, p.1263).

From the literature that I examined, I did not find research pertaining to what is on the web specifically for Canadian users. I also was unable to find research about information online for caregivers of adolescents with autism or moreover regarding autism in general in Canada. However, one study based in the United States conducted by Reichow et al., (2012) looked at what type of websites exists online when the researchers analyzed and evaluated websites which specifically addressed autism. In their search, they found the following characteristics:

"Free-standing clinic or organization	37.8%
Individual's site, forum, or blog	15.9%
Health informational website	14.6%
Government	8.5%
Online informational website	7.9%

News agency	5.5%
Collection of links to other websites	3.0%
University	3.0%
Wholesale, manufacturer, retail, or publisher	3.0%
Other.	6. %” (p. 1266)

I believe that these statistics pertain to Canadians as well due to the cultural similarities between the two countries. From this information, it is clear that my research did not use at least 15.9% of World Wide Web content regarding autism, as I did not use an “individual’s site, forum, or blog”. This is because these websites contain information that comes from parents and therefore is likely anecdotal, and as such falls under my exclusion criteria. Additionally, I did not use information sourced from universities. This is because this information is generally academic in nature; as a result these websites would be excluded. Therefore in my initial search, I likely examined about 80% of information available online regarding autism. However, it is important to note that this does not mean that 80% of information that is available online is reliable and easy to understand, and moreover can be utilized by caregivers of an adolescent with autism.

There is also limited published research regarding how to evaluate the validity of websites. Moreover, I was unable to find any published research relating how caregivers of an adolescent with autism evaluate websites. The related articles I found were mainly focused on searching for medical information online (Eysenbach, & Köhler, 2002; Gagliardi & Jadad, 2002; Hansberry, et al., 2014). Unfortunately, these articles were not helpful in answering my research question. One article did directly seek to examine “is it desirable or necessary to assess the quality of health information on the internet?” (Gagliardi & Jadad, 2002, p.571). However, it did not provide a conclusive answer. One of the related research articles I examined utilized focus

groups and actually observing computer users. The results of this research clearly indicate that World Wide Web users are concerned about notions such as the “Authority of source”, “Readability” and “Outbound links” (Eysenbach, & Köhler, 2002, p.574) when it comes to their World Wide Web use. I as well believe this to be of concern, and as such I addressed them in my examination of online sources. Another notion discussed in this article was that websites are often created by young professionals trained in website development as opposed to experts in the medical field. As such, the content may be written by those who have a limited understanding on what the website seeks to address. As one user states: “remember how, what for, and by whom the World Wide Web has been developed. It has been developed by 18 year old chaps. We shouldn't forget that these young fellows are putting up this crap without having a clue about what knowledge really means” (Eysenbach, & Köhler, 2002, p.575). Regardless if this notion is actually correct; it may serve to add an extra layer of mistrust to the contents of these websites. Moreover, the parents of adolescent tend to be a lot older than “18 year old chaps” (Eysenbach & Köhler, 2002, p.575). I believe that these challenges evaluating information online are applicable to caregivers of adolescent with autism as well, even though more research is needed in that specific area.

Description of Initial Search

Checked: 1,017 links include:

Links to websites

Links to appropriate pages in much larger website

Links to reoccurring websites: different links to same website

Links without actual website (dead links)

Findings

(See Appendix A)

169 links that potentially pertain to my topic:

These results of my search were separated into 5 groups:

1. Websites with a readability level below the 12th grade level:

Initially my goal was to find websites with readability under 11th grade, however due to the scarcity of these websites; I raised my readability to the grade 11th level. The readability is very important since the websites are meant for a busy user that has a limited amount of time do to their research on the World Wide Web. Therefore, in a short time the user must understand and process the websites information and make an educated decision if this information is useful for them and then act accordingly. Many caregivers of adolescents with autism due to many years of caregiving and dealing with a variety of services and treatments are familiar with autism terminology (Ho, 2016). Therefore, it is safe to assume that in caring for an individual with autism, the readability of the caregiver is higher than the average parent. This is only my

assumption based on caregiver of adolescent profile; however I did not see any research about this specific area.

2. Hubs/links to other websites:

According to Reichow et al. (2012) collection of links to other websites make up about 3% of all websites regarding autism in United States, therefore I can assume that this percentage is similar in Canada. In my World Wide Web research, these links were often a part of a much larger website, although there are few websites that consisted entirely of links. The links I chose to include (from the websites where links are a part of a much larger website) in my tables were mainly on the first page of the website and not hidden within other content.

3. Specific pages related to my research from websites with a much broader focus:

For example, the website from the Canadian government contains numerous pages, however, only a few of these pages pertain to my research focus. I found these pages through links from other websites. From my experience conducting this research, I believe finding these specific pages on such a broad website without links is near impossible without relevant previous knowledge such as how to locate the specific pages within the website.

4. Reoccurring websites:

Many of these websites have higher than an 11th grade level readability level, however, they appear more than twice within different list of helpful links on various websites. Many of these reoccurring websites are organizations that a typical caregiver often encounters, and as such despite their high readability level I choose to include them as well.

5. Miscellaneous:

This miscellaneous group of websites was included because although their readability level is high, these website address issues that I believe are of interest to the caregiver.

Specifics of My World Wide Web Search:

The results of my World Wide Web research capture the specific moment in time when I evaluated the website. Websites are dynamic; constantly changing over time therefore when the same website is viewed at a later date, the website may be altered. As such, I strongly recommend that my World Wide Web research be replicated at a later date in order to ensure accuracy in an ever evolving digital age.

Clarifications of group's titles:

1. Brief Explanation: This description does not always include a full description of all the content of the website. It is simply a short explanation of the section of the website that pertains to my topic.

2. Reliability of information: under this heading when it is noted that the reliability of information is inconclusive, I am not implying that information presented by the organization is unreliable. In fact, from personal experience with some of these organizations, I can say without hesitation that I have met several dedicated and proficient professionals. However, when within these websites there is no clear indication of an association with the government or any other reputable organization such as a university, hospital, etc., it is difficult for me to evaluate if the services that this particular website offers are optimal for an adolescent with autism.

Comprehensive Summary of Findings

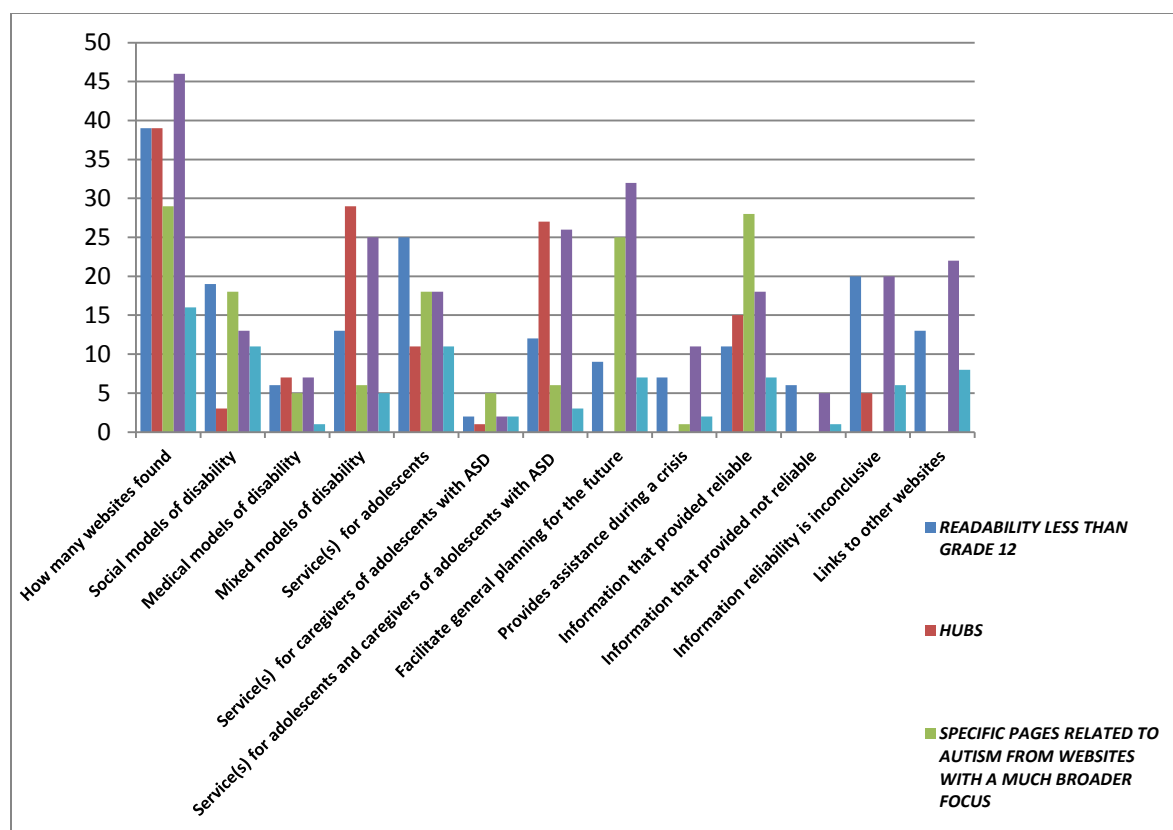


Figure 8

Websites that I found are covering many themes and areas that potentially can assist caregivers of adolescent with autism. Recurring themes include:

Family support includes respite services for all disabilities, all ages, and mental health (not legal or financial)

General autism information

Camps/recreational activities

Medical therapies/hospital

Mental health and suicide prevention

Rights, policies and other legal issues

School and higher education related issues

Inclusion services

Additional important themes that only few websites dealing with:

Abuse and bully prevention

Computer application

Connecting to other individuals in the society

Discount or accommodated admission to entertainment,
flights and other general venues

Financial assistance and planning for future

Life/social skills

Lifestyle magazine

Residential treatments

In this paper I will not discuss individual context of these websites and concentrate on more broad features that these websites consist of.

Points for Discussion

Information Searched for Versus Information Found

In my initial Google search, I used very specific keywords (Autism, Services, Family, Caregiver, Adolescent, and Ontario). The websites that resulted from my search were broad and the content, although related, did not precisely match the topics I searched for. As evident from my initial World Wide Web search, finding appropriate websites is a very time consuming and frustrating process, and does not always produce useful and credible results (see Methods for the Overview of World Wide Web Information for criteria for evaluating information). This occurs not because of a lack of results, but due to the search process itself. The online sources that did relate to my topic were a result of checking the links on the websites I initially found, with more links from there. In many cases, I found websites that discussed issues not applicable to my topic; however, some of the links from these websites did indeed relate specifically. In an effort to find quality information, the process almost always required several steps: examining certain websites, checking the links on the websites, and then potentially checking the links that were found on these websites and so forth. This process was often repeated for a significant length of time. This experience searching for quality online information closely mirrored findings in published research, in regards to the frustration caregivers feel in their own search for information. As one parent states, “it’s like trying to run through a maze blind folded” (Moodie-Dyer et al., 2014, p. 355). As such, it is clear that searching for quality information can lead to significant frustration for caregivers. I believe this experience can result in caregivers not fully utilizing the World Wide Web as a reliable source of information. This is despite the fact that accessing the World Wide Web is one of the widest spread, most readily available, and well used practice (Hansberry, et al., 2014).

Viewing Autism as an Individual versus a Societal Issue

Many websites such as those from well-known Ontario autism organizations such as the Geneva Centre for Autism or Surrey Place discuss different therapies for individuals with autism amongst other related services. However, it is important to note that even when these services are not solely based on the medical model of disability, the message that these websites convey is that it is the individual with autism who needs to change in order to participate in society, and not society itself that requires change. That is not to say that there is not value in adolescents with autism acquiring or improving important life skills (e.g. social skills). However, the problem lies wherein the impression given when accessing these websites; that autism is an individual issue and as such the individual with autism is the one that requires change rather society requiring change. Therefore, according to these websites (although they do not state it in these words), autism requires fixing, and is not simply a part of who someone is.

Readability Level of Websites in Online Search Results

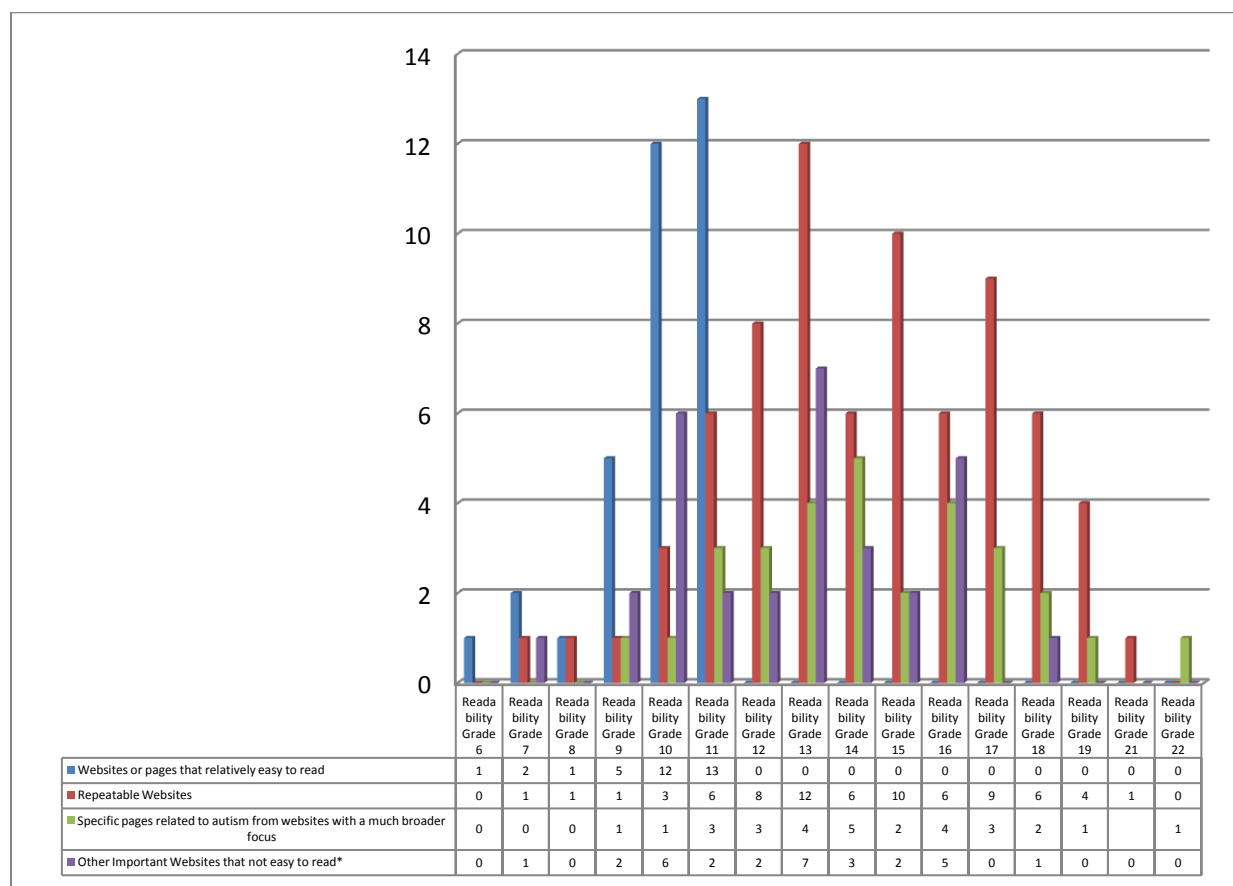


Figure 9

This table shows that the information available for caregivers of adolescents with autism is often presented with a readability level that is above the level of typical Canadian. In Canada, “48 percent of adult Canadians have low literacy skills that fall below high school equivalency” (ABC Life Literacy Canada, 2018), therefore it would be expected that the information presented on these websites should be below high school reading level.

My findings clearly show that any information online presented in a readability level below grade 7 is quite rare:

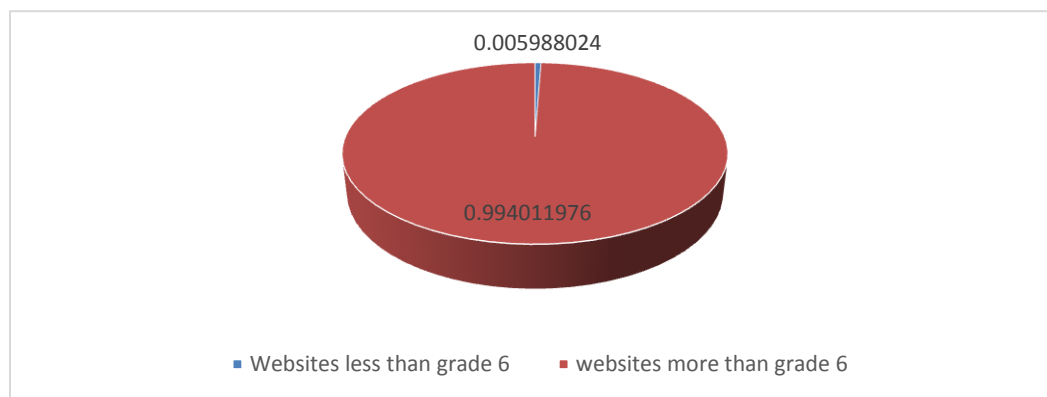


Figure 10

Even information online presented below grade 10 readability can be regarded as an anomaly as well:

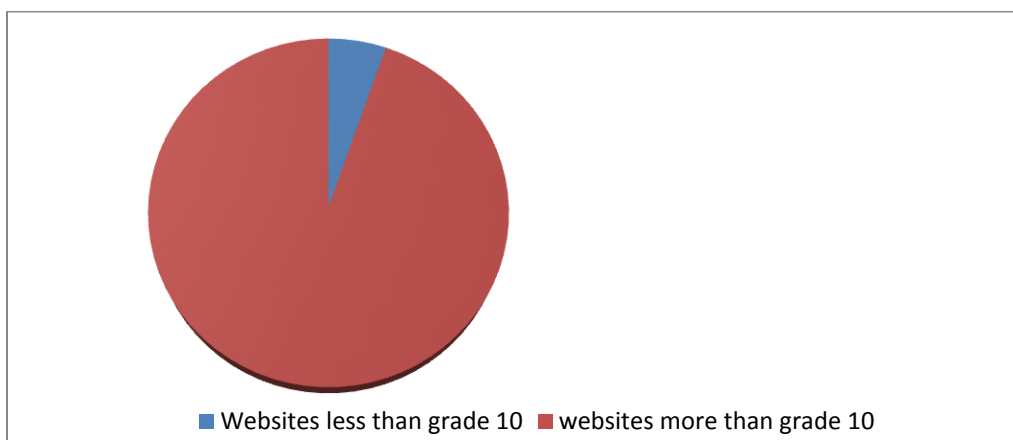


Figure 11

In order access caregiving information online, a caregiver needs to be able to comprehend information at a grade 12 readability level or higher:

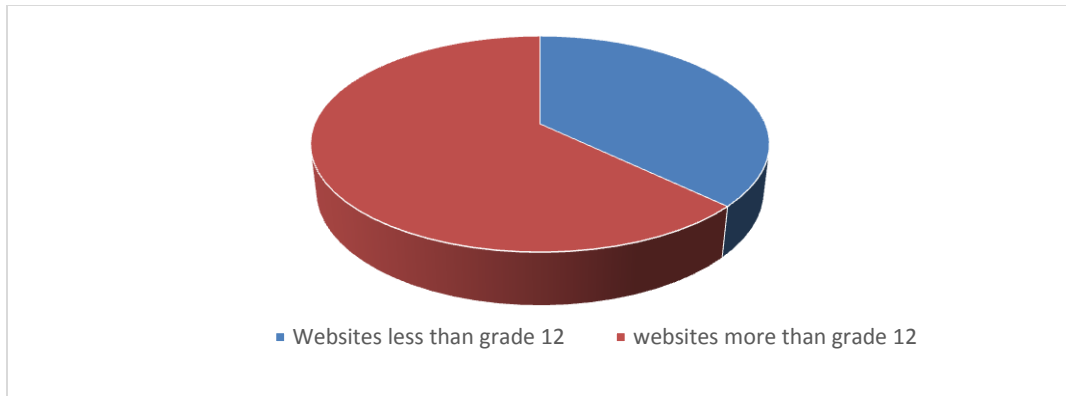


Figure 12

Ideally, they should be able to comprehend information at a readability level above grade 17:

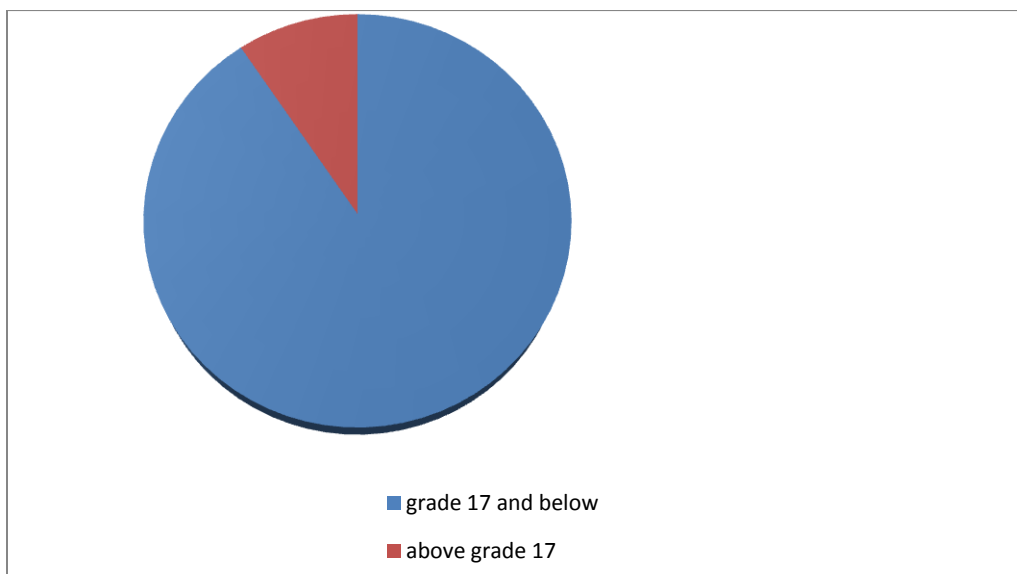


Figure 13

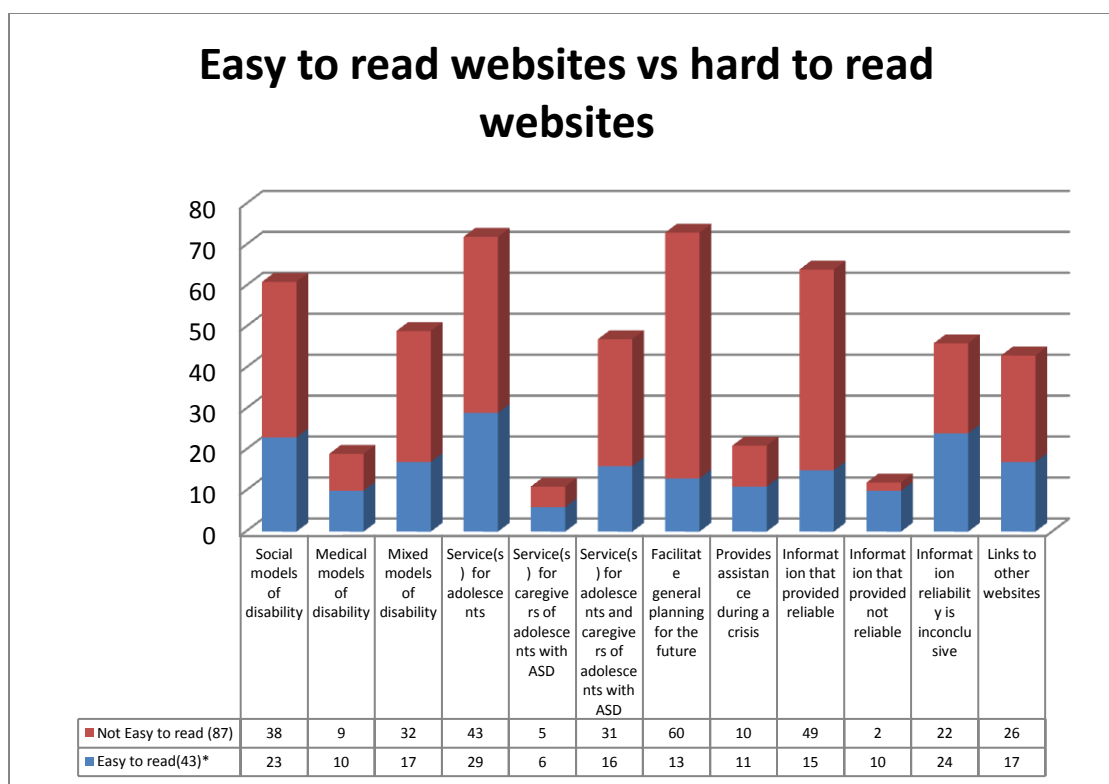


Figure 14

There are multiple websites such as *PREVNet: Research, Resources for Bullying Prevention, Autism Ontario*, etc. that are important resources for caregivers, and provide valuable advice and guidance. However, as shown in table above there exists somewhat of a language barrier for certain websites, as they use complex language that is not accessible for a typical user. This can result in the caregiver being unable to fully comprehend information that they find online or may result in misunderstandings. Difficulty understanding information due to complicated language can result in frustration for an already frustrated caregiver.

Misunderstanding information is a considerable issue as a caregiver may make an uninformed decision that can have significant and potentially damaging consequences. As discussed, from their years spent in the autism world, the caregiver of an adolescent with autism often becomes quite familiar with autism-related terminology (Ho, 2016). However, I did not find any published

research that supports the notion that by simply being aware of autism-related terminology, the caregiver has an accurate understanding of what the terminology is fully describing.

Additionally, my findings of high readability levels on autism-related websites mirrors research by Hansberry, et al. (2014), which focused on the readability levels of patient education materials from surgical subspecialties. This research found that even for online materials intended for patient use, the readability level was quite high as demonstrated in the following figure:

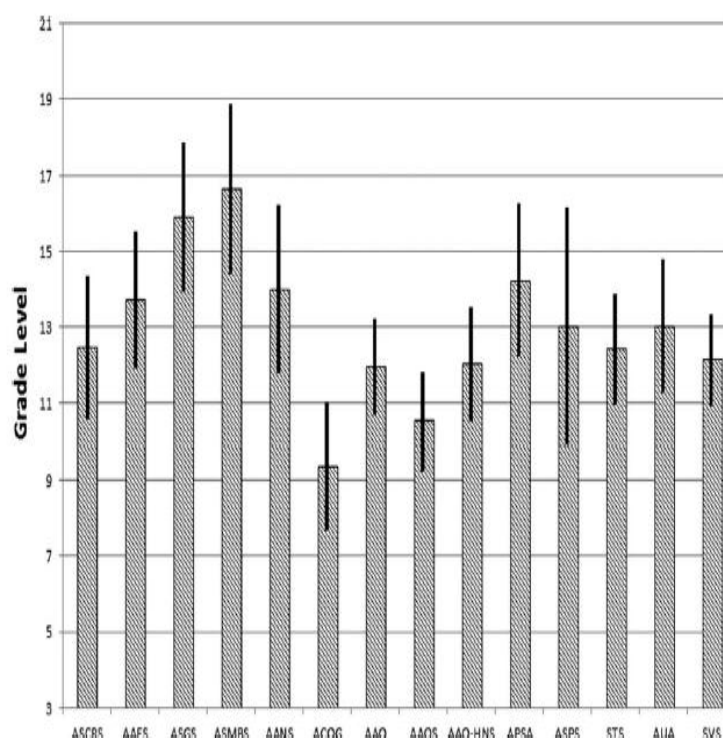


Fig. 1. Level of readability based on academic grade level as assessed by the average of nine readability scales for each surgical specialty's professional Web site. AAES=American Association of Endocrine Surgeons; AANS=American Association of Neurological Surgeons; AAO=American Academy of Ophthalmology; AAO-HNS=American Academy of Otolaryngology-Head and Neck Surgery; AAOS=American Academy of Orthopedic Surgeons; ACOG=American Congress of Obstetricians and Gynecologists; APSA=American Pediatric Surgical Association; ASCRS=American Society of Colon and Rectal Surgeons; ASGS=American Society of General Surgeons; ASMBS=American Society for Metabolic and Bariatric Surgery; ASPS=American Society of Plastic Surgeons; AUA=American Urological Association; STS=Society for Thoracic Surgeons; SVS=Society for Vascular Surgery.

Figure 15

Although this research does not address autism-related materials, it supports my findings that the readability level of informative websites is often higher than the readability level of the intended user. As a result, somewhat of a language barrier is created. This is unfortunate as these resources can be beneficial; however, they are not being fully utilized in the ways which they were intended.

Mental Health and Autism

Despite the fact that autism is a neurodevelopmental disorder (O'Grady, 2015) and not a mental health issue, there are some websites that resulted from my search such as the Woodview Mental Health and Autism Services website (which from the name alone suggests a connection) or the Centre for Addiction and Mental Health website that imply that this link exists. This can be problematic as it implies that an individual with autism needs to receive mental health treatment, as opposed to support that is directly related to improving circumstances for individuals with autism. Although it is important to note that individuals with mental health issues also deserve support and inclusion, treatment for mental illness does distinctly different from that of autism. Mental health issues and autism can of course coexist. Additionally, when an adolescent with autism or their caregivers do not receive adequate support, mental health issues can develop which may require mental health treatment. It is important to note that mental health issues are not as a result of the disorder autism itself. Rather, in some cases the circumstances surrounding the disorder can lead to mental health issues. For example, caregivers as well as individuals with autism certainly experience a large amount of stress, which can result in poor mental health.

Disability Models of Autism in Online Search Results

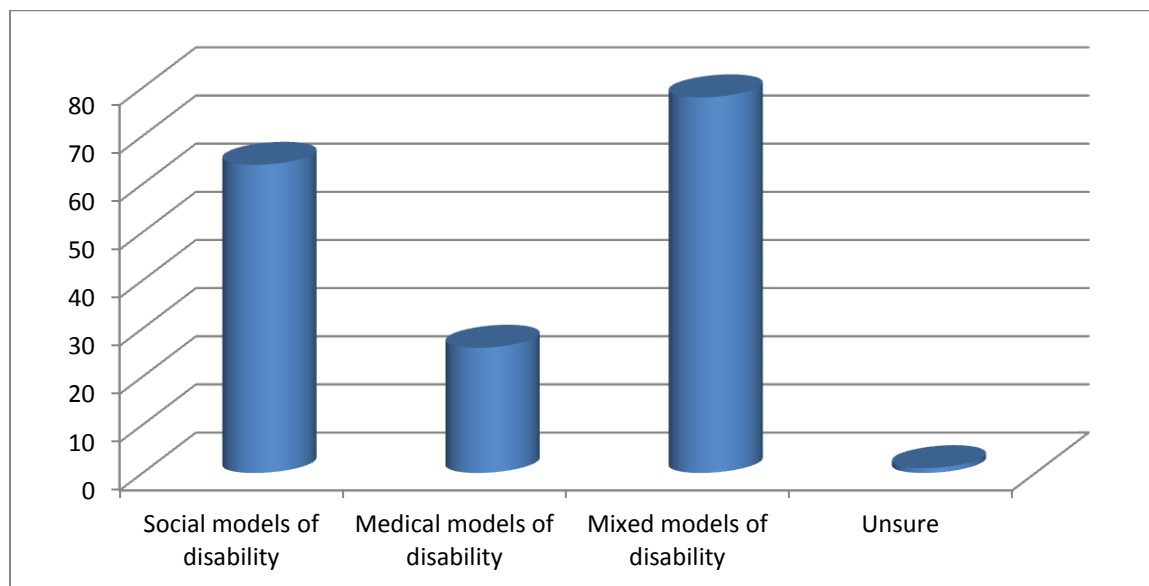


Figure 16

As exhibited in table above, from my search I found that websites from several organizations such as the Children's Hospital of Eastern Ontario Autism Program view autism mainly as a medical issue that requires treatment. These websites promote a variety of therapies for individuals with autism, and this demonstrates the dominance of the medical model of disability, which implies that autism is a problem that must be fixed. Even within the medical community, as discussed there is no consensus on the best way support individuals with autism (Adams, 2016) or even what causes it. From reviewing these websites, I did not see any mention of this lack of consensus, or any discussion of the necessity of taking an individualized approach to treatment.

Adolescents with Autism: Not Children or Adults

There are very few websites that I found in my search that specifically address adolescents as their own unique group. One example of a website that does is the East Metro Youth Services website. This website is not focused on adolescents with autism, but rather on the mental health of youth in general. Another example is the Best Buddies Canada website, which does have services for adolescents with disabilities, but is not specific to autism. There were a few websites such as the Ontario Pioneer Camp website that address children with autism, but I was unable to determine from their website that this includes adolescents. Furthermore, I was unable to find any websites that were solely dedicated to adolescents with autism and their unique needs. As previously discussed, autism is a spectrum and presents differently in every individual and therefore requires individualized support. It is very difficult to obtain appropriate information regarding adolescents with autism websites that address youth in general. Published literature also addresses the notion that there is a greater focus on young children with autism than on any other age group (Stevenson, & Gernsbacher, 2011; Stoddart, et al., 2013).

The Caregiver and Family Role

Target for Autism Services in Online Search Results

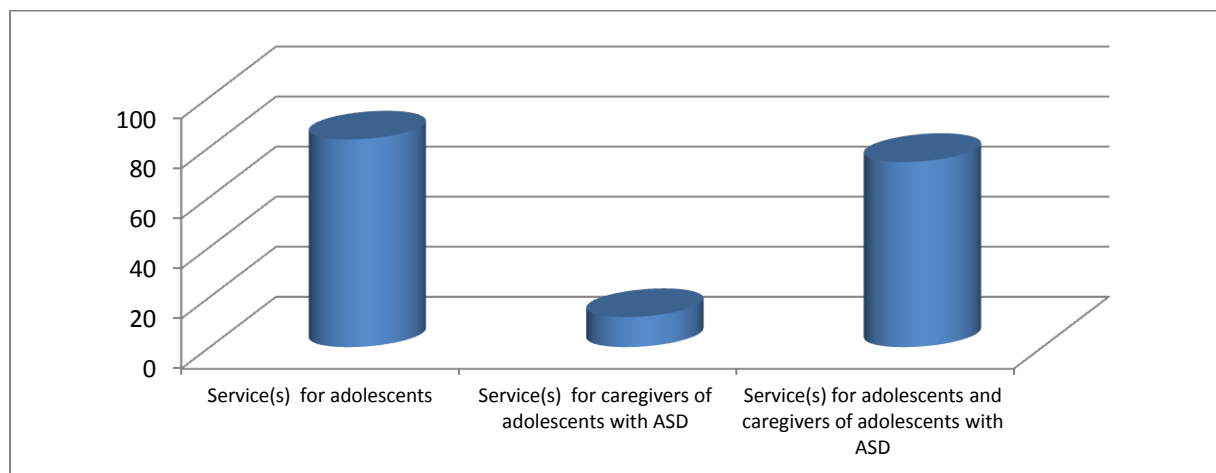


Figure 17

When families are addressed within websites such ErinoakKids, it is mostly through the view that a parent's most important purpose is to care for their adolescent with autism. The services for caregivers that are offered through these websites are mostly related to their role as a caregiver. There are websites, such as Extend-A-Family that offer a parent support group where parents can discuss any issues, not only those that pertain to their caregiving duties. Although this support group is not exclusively geared towards families of adolescents with autism, it is a positive step in the right direction. Websites that provide information about respite services (services that provide caregivers a temporary break from their duties) are another example of websites that are intended to support families. The organizations mentioned above may very well offer services for families that are not directly connected to their caregiving duties. I am simply stating that if they do it is not clear from their websites, and therefore a caregiver would be unable to find this information from an online search.

Websites Intended for Caregivers that Briefly Address Adolescents with Disabilities

Websites such as the Ontario Pioneer Camp or Just Bounce Trampoline Club website are geared towards caregivers, including those who have children that do not have autism. These websites do have specific sections related services for those with special needs that include adolescents. This information is extremely important and valuable, as it makes clear that these organizations support the integration of adolescents with autism in activities that other adolescents their age may participate in. These organizations generally support individuals with a various different disabilities, and do not focus solely on adolescents with autism.

Limited Websites Geared Towards Caregivers of Individuals with Autism versus Websites Regarding Disability in General

Only approximately ten websites that I reviewed such as the Autism Ontario website or autismcanada.org were specifically focused on autism. This is quite surprising given that autism is one of the fastest growing disabilities (Kogan, et al., 2009). As such, if a caregiver wanted to search for information online, they will need to search multiple websites regarding different disabilities in order to find useful information. Even when the caregiver searches websites that are focused on autism, it is not guaranteed that the caregiver will find useful information that can assist their adolescent and their specific situation. Therefore, more websites that are geared towards the needs of a caregiver of an adolescent with autism are still needed.

Viewing Caregivers as Professionals

Websites such as the AlphaBee website include sections that contain the same content for both professionals in the field and caregivers. Despite their good intentions, websites like this increase pressure on the caregiver as it can imply that the caregiver should be should have the same level of expertise as a professional in the autism field. Caregivers of an adolescent with autism often do have a higher expertise in autism (Ho, 2016) than the general population. However, website administrators should not assume that caregivers can comprehend information that is geared towards autism professionals. Caregivers of adolescents with autism represent a diverse group of people, and their level of expertise in autism varies. The message that this website can convey to the caregiver (even if it is not their intention) is that if they cannot fully comprehend the content, then they are not an adequate caregiver. These feelings of inadequacy can be a source of stress for the already overwhelmed caregiver.

Dead Links and Other Errors.

(See Appendix B)

Although this may seem like minor issue, when there are multiple dead links it can make one feel that the website administrator does not value their time, and also decrease the websites credibility. In their research Eysenbach and Köhler (2002) discuss a similar sentiment, stating that those who are responsible for these websites often do not fully understand the issues that the website address and in turn, lack an understanding of who the end users of their website are.

Outdated Websites

With numerous websites it is difficult to determine when it was last updated. In many cases, only after reaching dead links and as such wasting significant time, users learn that this website is not regularly updated. Although this sites may still able to provide valuable information, in our fast changing World Wide Web age website administrators must always ensure that the information on their website remains relevant. A quality and updated website represents a valuable organization that cares about the needs of their user. If a website is not regularly updated, the end user who may only be learning about this organization for the first time may be left with a negative impression of the services and/or resources that this organization provides.

Non-Canadian Links

I did not actively seek out these non-Canadian links, however, during my search I came across a few American websites such as <https://vkc.mc.vanderbilt.edu/healthybodies> or [Suicideline.com](https://www.suicideline.com). These websites although they may be quite informative and offer helpful services such as those found on <https://www.mentalhelp.net>, these services are not available in Canada. Many times the fact that this website is from the United States is not evident at first glance. Additionally, many users may make the assumption that since this link was found on a Canadian website it is applicable to Canadians, and then only after wasting valuable time does the caregiver realize that they are unable to access these services. This is another example of the difficulties associated with seeking out caregiving information online.

Reliability of Websites

As previously discussed, when it is stated in this paper that the reliability of information on certain websites is inconclusive, I am not implying that the information presented by the organization is unreliable. In fact, from personal experience with some of these organizations, I can say without hesitation that I have met several dedicated and proficient professionals. However, within these websites when there is no clear indication of an association with the government or another reputable organization such as a university, hospital, etc., it is difficult to evaluate if the services that this particular website offers are optimal for an adolescent with autism.

Reliability of Information found in Online Search Results

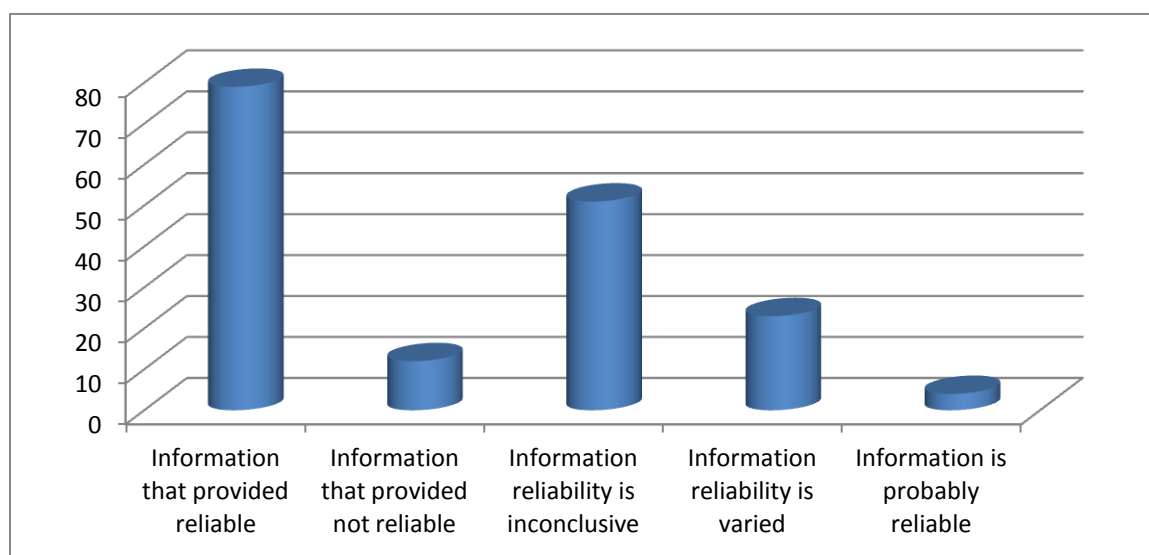


Figure 18

Conclusion

Throughout my extensive search, I did not find any websites specifically intended for caregivers of an adolescent with autism, therefore a caregiver has to search a vast amounts of semi relevant information to cherry pick something that potentially can be used. This finding supports my previous conclusion from my literature review; that caregivers of an adolescent with autism are often *not* perceived as unique group with unique information needs. I believe this to be the main reason for the lack of websites that cater to this specific group. Although when there are websites that provide information regarding services related to autism, it is implied that the end users will be caregivers of individuals with autism, and caregivers of adolescents with autism are a part of this group. Additionally, when pertinent organizations do not focus on this group on their website, since many times website is the face of the organization, the caregiver might miss opportunity to use this organization services.

It is apparent that some challenges when finding information on the World Wide Web are due to the notion of neoliberalism. There is a power imbalance between the organization behind websites and the end user. The main focus of many websites is on what they have to offer and not on the needs of an end-user. Their main goal is to “sell” their product; autism related services, regardless of if the service is appropriate for the end-user. They have a commodity to sell and they hold the power. This adds to the difficulties caregivers’ experience, as it can feel as though they are being used and taken advantage of, rather than being supported. Much of the issues discussed in this paper regarding websites that provide information for caregivers have been addressed previously in published research. As such, multiple issues discussed should already be known to and addressed by website developers and administrators. For example, readability formulas have been available since the 1950’s (Hansberry, et al., 2014), and therefore

website developers and administrators should be aware when the readability of a website is higher than the readability level of a typical user (ABC Life Literacy Canada, 2018). They should be also aware that a caregiver is often tired and stressed (Larson, 2010), which I believe is all the more reason why they would benefit from lower readability level. The readability level of this websites is a significant issue, as although websites may contain valuable information for caregivers, due to their high readability level it is inaccessible.

Despite their best intentions and efforts, a caregiver of an adolescent with autism is unlikely to be an expert in all aspects of caregiving. This includes evaluating the validity and effectiveness of caregiving information that they read online. Often caregivers are unable to effectively evaluate whether information from pertinent websites is relevant and evidenced based. It therefore should be the responsibility of the website developer to disclose the organization behind this website; how these services can benefit the end user; and if these services are endorsed by a credible organization, such as a reputable University or government. Many organizations in their websites elaborate about their board of directors; their philosophy, and their cooperation with other organizations; however without any well reputable entity that indorse this information it is up to the end user to perform additional task of validating the entity behind the website. I am afraid that this additional task for the already busy caregiver might reduced the benefit of using websites altogether.

It is justifiable to offer caregivers of adolescents with autism a variety of websites to satisfy their information needs, including websites that specifically address mental health. The issue is that caregivers who do not specify that they looking for mental health resources still find it and caregiver might get the incorrect notion that autism is a mental health issue that requires mental health solution. This is fundamentally incorrect but heavily suggested by search results.

Caregiving is difficult enough without the extra work of sorting through a large volume of information which is partially unsolicited, to find information that is applicable for them.

Website developers should offer a better way of ensuring the end user is able to find what they are looking for without offering potentially misguided information.

Current information on the web remains a scavenger hunt for information. This is because a caregiver of an adolescent with autism needs to access numerous websites in order to find adequate information that they can use. The issue is the vision behind these websites; not what the end user wants but what website has to offer. Instead of putting the caregiver of an adolescent with autism in the centre and asking what they need, in many cases the focus is instead on what the website is interested in promoting; and it is up to the caregiver to check it and decide if the content is useful. I believe that although websites have a full right to promote their services, they also should envision the end user and their need and invest more in explaining how their service or information that they promote will benefit the end user in their task of obtaining reliable and tailored to them information.

Next Steps

Although there doesn't presently exist one simple solution that can solve the information needs of a caregiver of an adolescent with autism, I have identified some practical steps that can be taken in order to alleviate these challenges:

Since caregivers search for information online (Tonsaker, Bartlett, & Trpkov, 2014), professionals such as doctors, social workers, and teachers who work in the autism field need to provide accessible and reliable information for caregivers of adolescents with autism. Moreover, the difference between the information needs of caregivers of young children, and the needs of caregivers of adolescents with autism should be emphasized. This information needs to significantly differ, because adolescents and children significantly differ.

These professionals should be encouraged to actively look for solutions to support caregivers to obtain information that is specific to the caregiver's specific situation. These professionals need to be aware that the people that they assist are using the World Wide Web to obtain information relating to their needs. Autism professionals should be familiar with websites that pertain to their area of expertise, as they are uniquely equipped to evaluate the validity of website contents, much more so than the typical caregiver. As such, they can recommend appropriate websites that can help their clients and/or patients.

Furthermore, I believe there should be a campaign educating the public including caregivers on the dangers of obtaining information online. The public needs to be made aware that not all information on the World Wide Web is equal, and question the source of what they are reading and if there is any motivation behind the websites sharing this information. This awareness will help ensure we all become smarter consumers of the World Wide Web. Caregivers of individuals

with autism especially need to be made aware of this issue, and also be aware of the fact that although it sounds quiet cruel to view autism websites from a consumer point of view (Reichow, et. al., 2012); in the eyes of many online agencies, autism is commodity like any other. Moreover, an educated World Wide Web user has a higher probability of obtaining reliable information that suits their needs. The World Wide Web dangers awareness campaign should also be geared towards professionals who are working with individuals and their families with autism as well.

I strongly believe that there is a need for additional research in an effort to find an answer to my research question: when caregivers of adolescents on the autism spectrum search online for information related to caregiving for their child, what information is available? This research paper only begins to address this. For example, I only conducted this search for information online one time, (although it took several months to carry out) and it is possible that these websites will change in the future, or have already been modified. To ensure the information needs of caregivers receives the attention it deserves, this search should be recreated in the future to ensure current issues with these websites are brought to light. Additionally, this search being repeated by an individual with a different background will serve to make this research stronger, as they may identify other important issues and gaps.

Additionally, I believe that there should be more research about needs of caregivers of adolescent with autism from an interdisciplinary point of view. These researchers can conduct participatory research that incorporates the caregiver perspective and will benefit both individuals with autism as well as the caregivers. The “NOTHING ABOUT US WITHOUT US” (Derby, 2013, p.375) principle should be applied. This principle discusses that when doing research regarding disability, the views of individuals with disabilities should be included. As

such, autism research should incorporate the individuals with autism, and I believe their families as well. Only by including these viewpoints will researchers be able to provide valuable and effective ways of supporting these families. Additionally, researchers who conduct research in autism should also ensure that their research is able to be understood by caregivers. When possible, researchers should create a simplified version which includes the important aspects of their research in a way that the caregiver can read and comprehend.

An additional action that can be taken to support caregivers is the development of a website that will put the caregiver of an adolescent with autism at the centre; and offer an appropriate response to their information needs. This website will act as an online portal specifically for caregivers, who often need a timely, concrete answer to a concrete problem. This website should present a full picture of all the information that caregivers may need in a clear and organized manner, without using unnecessary professional terminology. This portal could possibly include:

- A brief and clear explanation about the social and medical model of disability and how it relates to caregivers
- A glossary of terminology that experts in autism often use
- A list of subjects that may be of interest to the caregiver, with an explanation of every subject written at a readability level of grade ten and under
- Links specific pages of websites that may be of interest to the caregiver
- When links to websites regarding therapies are listed, there will be a clear description of these therapies which includes possible benefits, side effects, length of therapy, cost, location etc.

- A section dedicated specifically to the caregiver wellbeing. This section will be consist of two parts:
 - Clear and accessible information regarding the physical health, mental health, and financial challenges that caregivers may experience
 - Advice how to mitigate these challenges and specific organizations that can be helpful

These steps will not solve all the challenges that caregivers of adolescents with autism experience, but they can significant help caregivers by ensuring that they are able to make more informative and potentially better decisions. This steps can as well provide some comfort to caregivers on a personal level, as they will feel that their experiences are valued and that steps are being taken to better their situation. However, it is extremely important to note that despite these challenges providing care for adolescents with autism is a meaningful and enriching experience. My son is a bright and sweet young man who brings me and my family immense joy and pride. It is my hope that by advocating for reliable and accessible information for caregivers, the gaps I identified will be addressed, and myself and other caregivers are better able to provide care and support for their children.

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Appendices**Appendix A**

See attachment

Appendix B

See attachment