THE ILC FOUNDATION | 10 years
Chronic Pain Ehlers Danlos HCTD

Needs Assessment

ILC Charitable Foundation

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School of Rehabilitation Science
REACHING FURTHER

McMaster University

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Section 1: Purpose

Purpose

The ILC Charitable Foundation is a non-profit organization, motivated to help bring awareness to a rare condition called Ehlers Danlos Syndrome (EDS), which is a group of rare disorders that affect connective tissue. This disease is poorly understood within society and can go undetected for many years without the right supports. The ILC Charitable Foundation helps to advocate for individuals presenting with EDS and other Connective Tissues Disorders, diagnosed or not, and help to navigate the healthcare system, such that individuals are able to get the supports and resources they need to improve their quality of life.

Student Occupational Therapists, Alexander Dos Santos and Zeenal Mistry have had the opportunity through the McMaster University Occupational Therapy Program to complete an eight-week virtual placement from March 15th, 2021- May 8th, 2021, at the ILC Charitable Foundation located in Canada. Over the past eight weeks, the Student Occupational Therapists interacted and interviewed members presenting with EDS and other comorbidities related to this disease, to inquire more about their experiences living with a rare and chronic disorder, and their interactions with various systems.

The purpose of this report is to address the unique needs of this population, identify the gaps in the system, and outline the next steps to help eliminate the identified gaps and to enhance healthcare. A visual mind map was created to portray the interconnected and interdependent themes of the EDS population. Through this placement, six major themes have been identified: Presentation of Symptoms, Institutional Gaps, Healthcare System Gaps, Social Supports, Impacts due to COVID, and Further Research. Within each of these themes, the needs of the EDS are further discussed. As demonstrated within Figure 1 (Refer to the Appendix), the needs of the EDS population are as complex and interconnected as the condition itself, which highlights the challenges faced by this population. Client-centered care has been recognized at the core of these identified themes and encompasses active listening, empathy, and autonomy as well as many other aspects that is required to help enhance health and well-being.

Overall, this report will address the needs of the EDS population, however, it is important to be mindful that these are not the only needs out there for individuals with connective tissue disorders. Throughout this report, it should be acknowledged that while the focus is on those with EDS, however, many individuals with other connective tissue disorders, have similar challenges as well. In addition, a challenge with EDS is to get diagnosis, therefore, this report recognizes individuals without a diagnosis as well. It is evident that with more time and resources, additional needs may emerge as it has been understood that this population is diversely unique.

Section 2: Client-Centeredness

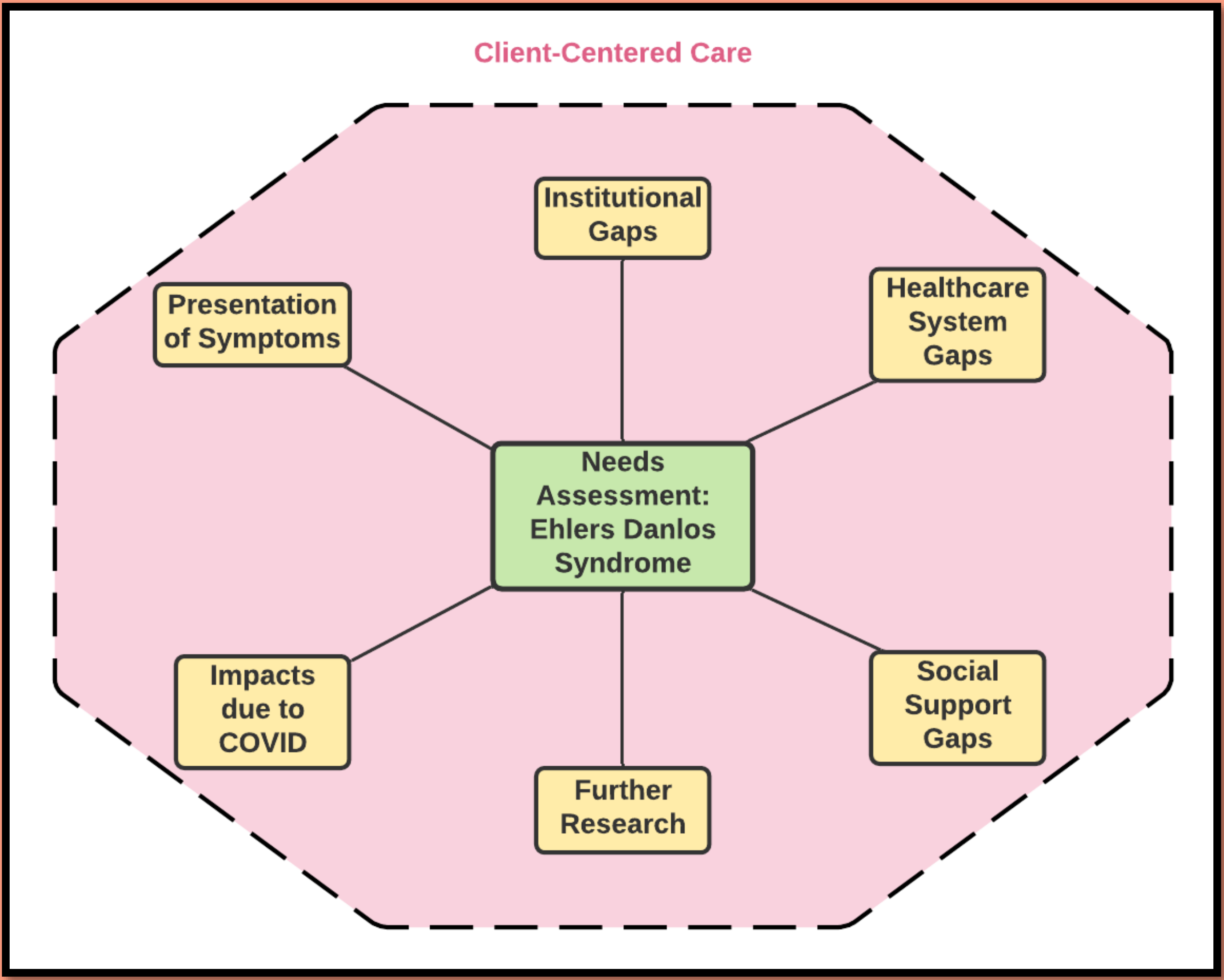

Figure 2: Client-Centered Care

Client-Centered Care

Client-centered care allows patients to be empowered and autonomous in their own healthcare and focuses on respecting one's needs and what they value in terms of their life and their health. Healthcare providers who adopt this approach are better able to understand their patient's needs through active listening, thus, provide treatment that they know their patient's will adhere to. As a result, the patient's quality of life is improved as their healthcare is tailored around their needs, and they are given the space to advocate and voice their concerns as required through developing a therapeutic relationship with their provider. Active listening and empathy are also a big part of being client-centered and needs to be revisited for healthcare providers as these skills can drastically change the therapeutic relationship and the care received. Therefore, it is evident that client-centeredness is an important aspect of healthcare and the benefits need to be better recognized amongst the healthcare community.

The Ehlers Danlos Syndrome population present with unique and specialized needs that are unfamiliar to many healthcare providers. As this disease is rare, and complex in nature, a client-centered approach to healthcare can allow individuals to be more confident in confiding in their healthcare provider in regard to their concerns. There are many challenges that the EDS population face, which are discussed in the sections below. The main theme throughout is that client-centeredness is essential in order to help individuals with EDS receive sufficient care and make the most of their lives with the support from the medical community through highlighting the importance of their needs and values.

Section 3: Presentation of Symptoms

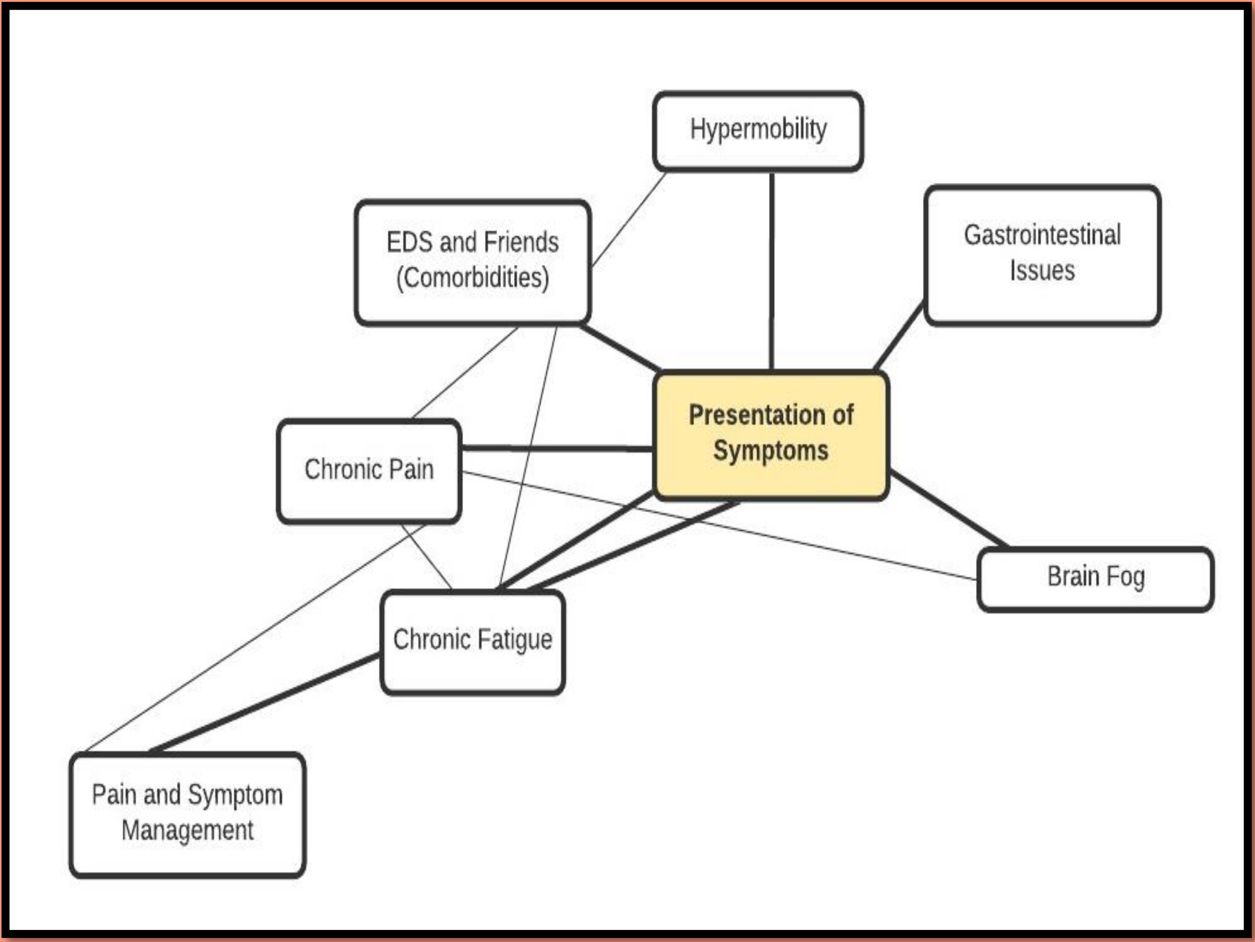

Figure 3: Presentation of Symptoms

Presentation of Symptoms

This Section: Key Points

- **Overview of symptoms and common presentation of symptoms to set the stage for the rest of the Needs Assessment.**

EDS embodies the word heterogeneous quite well. This disease has 14 different subtypes of classification involving multiple genetic markers, and various parts of the body. There are also many symptoms that are linked with each type of EDS. Additionally, there can be multiple comorbidities linked to the presentation of EDS as well. Each person has a different presentation of symptoms and they also put different demands on themselves to complete the various meaningful occupations in their life. The management of these symptoms provides a unique set of challenges for each person living with them as well as the team that helps to care for them. The list of symptoms presented below helps give context to the experience that underlies each individual in terms of what they need to manage to help them engage in their everyday life. This is not a comprehensive list but is meant to keep in line with being client centered by focusing on the challenges that affect the client the most.

Common presentation of symptoms:

- Generalized Joint Hypermobility
- Soft or fragile skin
- Chronic Fatigue
- Chronic Pain
- Brain fog
- Insomnia

- Metabolism of Medications
- Gastrointestinal Difficulties
- Depressive Symptoms
- Anxiety

Common comorbidities:

- Mast Cell Activation Syndrome
- Postural Orthostatic Tachycardia Syndrome
- Dysautonomia
- Dercum’s Disease
- Tethered Cord Syndrome
- Intracranial Hypotension
- Chiari Malformation
- Retinal Tearing
- Tarlov’s Cysts
- Autism
- Attention Deficit Hyperactivity Disorder
- Aortic Dissection
- Post-Traumatic Stress Disorder (Medical and Otherwise)

More information will be provided in the following sections regarding the gaps experienced by each in the Canadian healthcare (and other) systems regarding the above symptoms.

Next Steps:

- **Research regarding the most common symptoms and comorbidities.**
- **Increased awareness of these symptoms to health care professionals.**

Section 4: Institutional Gaps

A. Perceived Values Within Society

- Pediatric and Adult Care
- Transitions from Pediatric to Adult Care
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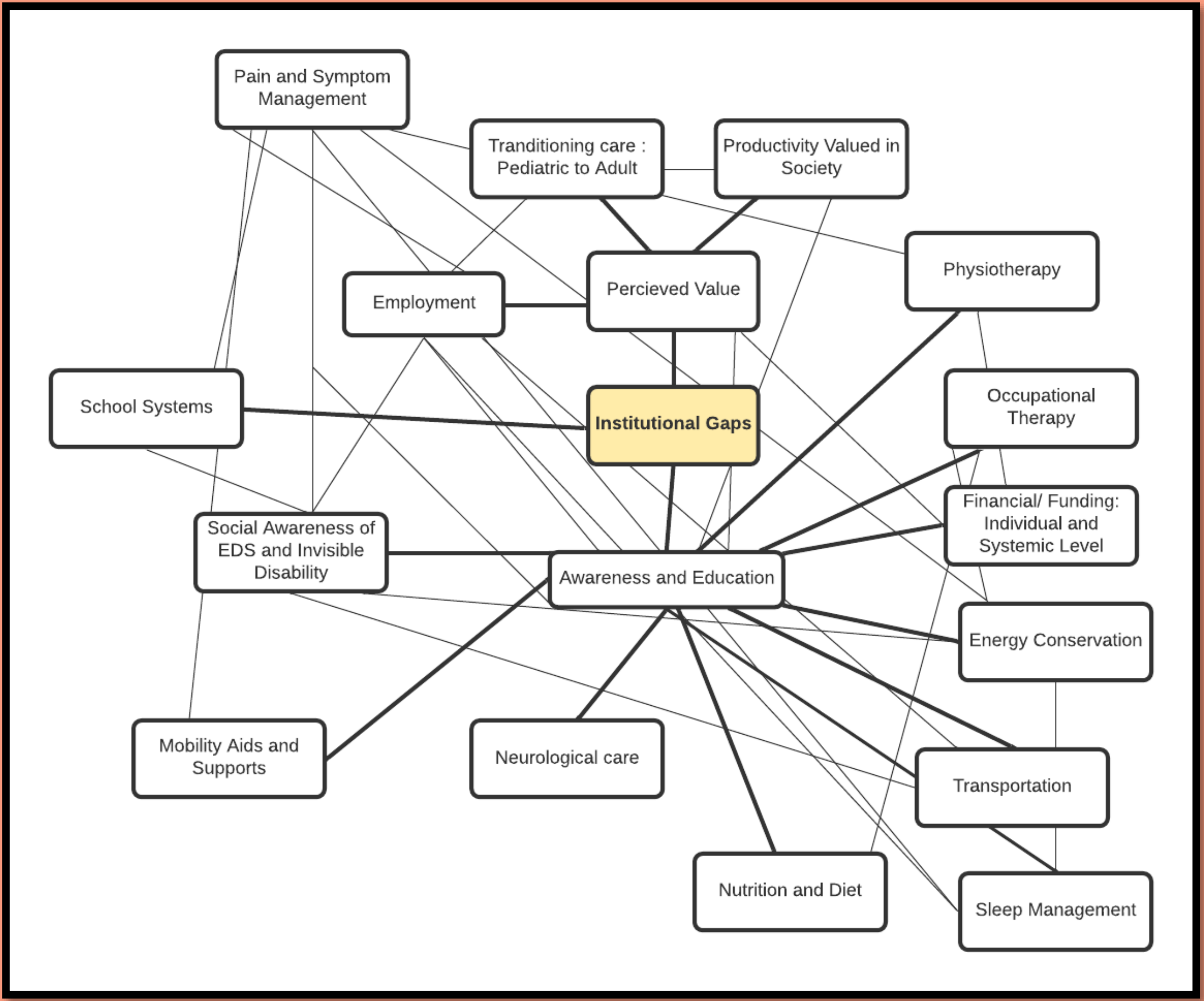

Figure 4: Institutional Gaps

A. Perceived Values Within Society

Pediatric and Adult Care

This Section: Key Points

- **Resources are funneled into pediatric care more often than adult care.**

There is less care received as an adult in comparison to care that is provided for the pediatric population. When an adult is suffering with a condition like EDS that is complex, and presents itself differently every day, it is difficult to get an optimal level care due to many challenges related to stigma and labels. Children are more likely to have increased support and care because they are less self-aware of their emotions to express them maturely. Since a child may not be able to effectively communicate what is wrong, it is expected to be within the pediatric providers hands to be thorough and consistent in their care. More often, providers will go out of their way to look for any abnormalities presenting within children to catch it early and be able to treat it. Yet, as people grow older, they are more aware of their body and are more expressive of their needs; care for adults starts to get worse as they age. Due to the lack of expectation by providers, adults tend to be written off as being "whiny" or seen as complaining too much, and therefore, are not taken seriously, and physical illnesses are not further investigated. This is common situation within the EDS population where many of their symptoms are undermined by healthcare providers. These concerns are not investigated as thoroughly as they are for other chronic conditions, and many individuals end up suffering for years without any management or a diagnosis. This has been a theme for those with EDS as they have gone years through the system not receiving the care needed. The biases and resources presented by the differences in adult population to the pediatric population makes it increasingly difficult to care for those affected by EDS or likewise symptoms after they turn eighteen.

Next Steps:

- **Leveraging the pediatric population to help with diagnoses of those with EDS.**
- **Increasing awareness of the implicit biases within health care providers to aid with funding for adults.**

Transitions from Pediatric to Adult Care

This Section: Key Points

- **There are poor transitions between the pediatric and adult sector of health care.**

The transition from pediatric care to adult care has also been expressed as challenging for those who have been in the healthcare system as a child. The pediatric team tend to be more familiar with the child's health history as they have been following them through development. However, while young adults are transitioning between different care teams, knowledge and expertise is not sufficiently carried forward to the adult sector. Young adults are then left with a care team who is new to their condition and presenting symptoms, which compared to their pediatric team, are not cared for in the same way. As a result, individuals with complex needs find it difficult navigating the healthcare system as they are left with a lack of support and find themselves having to advocate more for their needs compared to what they were used to. Additionally, getting supports is also challenging due to the lack of aid and complex policies within the adult sector of care. This transition can be adjusted to be more comprehensive on supports that the client needs and how to help them navigate to get the resources that they need.

Next Steps:

- **Increasing focus on transitioning to help with the resources that are needed as one becomes an adult to help navigate the healthcare system.**

Gaps in Pediatric Care

This Section: Key Points

- **There is a power dynamic that healthcare providers have that can influence minors and their parents which can limit optimal care.**

There is more attention to care during childhood, there are still gaps in the medical system when it comes to addressing the complex needs of younger patients presenting with EDS at this stage of development. For example, children or adolescents may be labelled as “attention seekers” or that they are “faking it” which causes symptoms that may be dismissed, and adequate care not received. Children and adolescents also do not have much agency in their care while working with adult practitioners as many adults think they may not consider what is going on. Children tend to be more familiar with their body and what is happening with their health as they grow older within the medical system, and thus, can be more knowledgeable than healthcare providers are aware of. Many individuals with EDS who have grown up being in the healthcare system have found that they wished they had more autonomy in making decisions regarding their healthcare Individuals have described that their healthcare providers did not listen to them and portrayed that they knew best. This power dynamic had put the young patients in uncomfortable situations where they were unable to express their concerns. Additionally, parents of children, especially mothers, may be labelled as having Munchausen syndrome, or hysterical for trying to advocate on behalf of their children in terms of their health experience. Since EDS is not well known, healthcare providers are unable to find explanations for causes of children’s symptoms and may tend to stigmatize mothers for worrying for their children. This lack of trust from healthcare providers to the client and/or their parents and guardians still presents with challenges for those with EDS regardless of age.

Next Steps:

- **Listening to children and adolescents as people as well as taking their agency into consideration is important for health care providers to continue doing what they need to do.**
- **Transparency between healthcare providers and the patients are important to ensure the best quality care for patients.**

Productivity and Employment

This Section: Key Points

- **Productivity that is valued so highly in society and when members such as those with EDS cannot be as productive, it creates the sense of lesser value.**
- **Changes can be modifiable based upon the environment.**

Society tends to associate one's value with productivity, which creates an atmosphere where one's work defines everything. Individuals with disabilities have expressed that they feel excluded and dehumanized in this fast-paced society, as many are unemployed or unable to work full-time. While individual forces such as physical or mental limitations may impact one's productivity, the external societal forces further limit the ways that individuals with disabilities are able to participate in society. Individuals with complex, rare disorders are at an increased disadvantage as they do not have a formal diagnosis, and therefore, do not meet the criteria to get accommodations in their line of work. Additionally, those with an invisible disability, like EDS, have decreased support due to not being believed by the healthcare system, and being labelled as "lazy", further preventing individuals with disabilities from participating in a productivity-based role.

Within society, there are limited opportunities for individuals with disabilities to work. These opportunities are restricted based on bias and stigma towards disabilities, as well as physical structures.

One barrier in the workplace is the associated discrimination and stigma towards individuals with disabilities that create feelings of exclusion and being less worthy compared to their co-workers. This further prevents individuals from wanting to participate in the workforce.

Specifically, those with an invisible disability like EDS, may be further be misunderstood in the workplace due to co-workers not understanding why accommodations are given or required, especially when it may seem that the person looks fine. Since EDS presents itself differently every day, it might be challenging coming into a workplace where judgement is felt due to a lack of awareness of other sensitivities. Hence, there needs to be more education and training within the workplace amongst employers and employees in relation to supporting individuals with invisible disabilities to eliminate these barriers. This can help provide an inclusive environment for everyone working there and can help create further opportunities for those with EDS.

The design of the structures also acts as another barrier to participating in the workforce as many structures are still not made accessible to those with disabilities. The lack of accessibility in the workplace further devalues those with disabilities and portrays a negative message to those that want to pursue a career in the industry of their choosing but feel as if they are unable to because of the physical barriers they have no control over. This design of lack of accommodations for different jobs can create challenges in making people more hesitant to find a job that suits them. Having a disability such as EDS limits the number of opportunities that are available regarding employment while many of them are things that can be changed.

Overall, living in a society where one's value is associated with their work, there are many challenges and barriers that prevent individuals with disabilities from contributing to a world that is heavily driven on productivity. When there is a lack of accommodations present and the willingness not to support those with disability, the message that is sent is that people with disabilities are of lesser value than the able-bodied person. More support is necessary for individuals with disability, and more opportunities for them to engage within the work setting needs to be recognized.

Next Steps:

- **Changes regarding physical, social accommodations and opportunities can create a more productive and optimal situation for people living with EDS.**
- **Recognizing more roles within the work setting for individuals presenting with disabilities.**

Decision Making in Society and Biases in Powerful Positions

This Section: Key Points

- **Large decisions that influence many are mostly made by the white, older, straight, able-bodied male.**

Outside of the EDS or even disability community, there are certain profiles of individuals that are more likely to be in a state of power and thus, can make decisions that impact the lives of many. This has been an ongoing issue in our national government and others around the world. The most prominent profile that has power in society is the older, straight, able bodied white male. The system that we live is littered with white males in power. One theme that has come up repeatedly is the lack of decision making by those that are affected by it. Continued efforts to include the population affected by policies and decisions by those in power are needed. Additionally, continued effort to promote distribution of power to those with disabilities, minorities, women, and those in the LGTBQ community within the power structures that influence others are important. This would help create a government that is overall more equitable and considerate to other minority groups as it is based on the common humanity that we share as opposed to the differences that we find in the situational lack of ability or differences in the experiences, sex, skin, colour, gender, and ability that we all have.

Next Steps:

- **More equitable distribution of power in the system can help create a better. system that helps create policies that are more inclusive and considerate to other groups.**

B. School Systems

Gaps within School Systems

This Section: Key Points

- **There are issues with invisible disabilities in the school system and staff not trusting students about their own disability, especially when undiagnosed.**
- **Honest communication between the institutions and its students are important to promote learning with whatever accommodations necessary so that students are supported in their education.**

There are many gaps within the school systems that prevent individuals with EDS from being the best student they can be. The lack of education and awareness regarding EDS is a large barrier in understanding the accommodations and supports needed for students who present with this chronic illness. Since this disability is largely invisible, administrators and staff do not recognize the need for the support that the student requires to be successful. For instance, an occupational therapist may be called to observe the student's behaviour in a classroom setting to identify their specific needs. However, this evaluation is not reflective of the student's challenges as EDS presents itself differently each day, and some challenges cannot be seen solely through observing a one-hour session. As such, due to not being able to observe the problem directly, concerns are easily dismissed, and students presenting with EDS symptoms are unable to get interventions or support that could later be of benefit in the future when it comes to their learning. This can also completely gaslight them because it invalidates their own experience and their pain. Thus, it is important for administrators and staff in the school environment to be trained on how to support and evaluate students that present with invisible disabilities, like EDS, to provide the necessary accommodations to support their learning.

It is even more challenging to get ongoing support within higher educational systems. As mentioned, is it difficult to receive accommodations when students present with an invisible disability. In such instances, having written evidence of the needs by a healthcare professional is beneficial to supporting the student in receiving the required accommodations. However, for individuals presenting with EDS symptoms who do not yet have a formal diagnosis, this can be challenging. Additionally, it is difficult for individuals with EDS to get support when the accessibility services and professors are not familiar with the symptoms of the illness. For instance, students may be labelled as “lazy” or “needy” when asking for accommodations solely because their disability does not present itself to school staff. Many individuals had also expressed their ability to mask how they are feeling, especially when they perceive a potentially hostile environment such as school. Being able to accept the student and the person for their experiences and their abilities is important to allow them to thrive in school.

Moreover, policies around accessible education also provides loopholes such that an accommodation may be provided if it is “reasonable”, which can be interpreted in many different contexts. Thus, students may not be granted the support required due to teachers’ principles and educational staff not believing them. This all relates back to the lack of education about rare conditions, like EDS in that it is largely invisible to the eye and can present itself in different ways. In addition, attitudes around disabilities being absolute, such that you either have it or do not, is dehumanizing. One day the individual may require a wheelchair, the other day they may not, however, this does not mean the person does not have the disability anymore. This perception portrays a negative message that negates the possibility of invisible disabilities. This is a dangerous concept as it not only affects people that have undiagnosed medical conditions that are not observable, but it completely stigmatizes other illness such as major depressive disorder, generalized anxiety disorder and other mental illnesses. These attitudes around disabilities can be damaging to the health and well-being of students, staff, and society as it can limit opportunities to pursue what people want to do as they age.

There are also many challenges within accessibility services at schools regarding how to ensure these supports are being used to it is fullest by students that require them. When students in higher education are seeking out support through their accessibility services, they usually do not know as to what accommodations are available or what they would need. For students presenting with EDS, it may be challenging to know what supports they might require, when some days they may not need the support, and other days they may. Due to stigma towards disabilities and not understanding accommodations within a student environment, individuals may feel that they will be judged for using specific supports, by peers or staff when they do not look like they need it. Thus, it is difficult for students to pick out and ask for supports that they will always need, and as a result, they may miss out on other accommodations that would have been of benefit to their learning This issue stems around the lack of education and awareness around disabilities within both the student environment, and the academic community. To prevent these problems, honest communication between the school services and its students are needed to ensure people thrive as they complete their education. A student presenting with EDS may not know exactly what they need, however, when given a list of supports that are readily available, they may be more comfortable knowing the accommodations that are available and can ask for them when needed. Additionally, those with EDS have specialized needs and may require unique supports that may not be on the proposed list of accommodations that schools have provided. Hence, in such cases, accessibility services and stakeholders involved need to be open to taking a collaborative approach to see how these unique challenges can be accommodated. By creating this inclusive environment, students with disabilities, especially those presenting with EDS, can feel supported, and empowered to make decisions regarding their needs and how they are able to learn.

Next Steps:

- **Promotion of awareness and education to the school system about invisible disabilities.**
- **Mandatory training within the school system on how to support students with disability.**
- **Increasing honest communication and collaboration within the institution and its members, especially students so that learning is possible, especially when a disability such as EDS is present.**

Mobility Aids and Perceptions within the School Environment

This Section: Key Points

- **Keeping a client centered approach to deciding when aids are necessary is important as aids and accommodations have different meanings for everyone**

On the flip side of invisible disabilities, wanting to stick out of the crowd with accommodations can bring about a new set of challenges. Transitioning into a post-secondary environment can present to be more challenging for individuals with disabilities when it comes to fitting in with their peers. When the symptoms and presentation of EDS are more visible, one may appear to feel embarrassed or self-conscious about their appearance and behaviour. In addition, at this developmental stage, there is a societal expectation of being independent and self-sufficient, which further influences the choice of being seen with mobility aids. For instance, being in a wheelchair, having a walker, oxygen assist, or even hand splints can be seen as unusual for a young person. As a result, those with disabilities may not want to use these supports with the belief that they may be able to survive without them within the university environment. This perspective adopted by the student is natural at their age, and can be expected, especially due to the stigma that is largely present around using aids. While those in the individual’s care circle may want to convince them otherwise, it is ultimately up the individual outside of possible substitute decision makers to use the aids and accommodations when they are ready. In these situations, it is important for healthcare providers, such as an occupational therapist to take into consideration and understand both the client’s needs, and their safety when it comes to mobility aids. Healthcare providers should make it known to their client that they are being heard, and to ensure that their client knows that supports will be there when they are needed. This helps to provide support for clients when they are ready for it because that is what is meaningful to them.

Next Steps:

- **Awareness and respecting the clients' decision in using aids and accommodations available to them**
- **Having accommodations available and on the ready when needed as well as the knowledge for the client to sue them is important**

C. Awareness and Education

Societal Awareness

This Section: Key Points

- **Judgement are constantly being done on people with invisible disabilities even when they are managing their pain**

Due to the large heterogeneity of symptoms, there is a discrepancy between what an individual with an invisible disability such as EDS needs and what is socially acceptable according to others. As mentioned above, there are many different facets to EDS and how it develops, majority of which do not explicitly show that the individual with the condition has it or any disability. For example, a form of chronic fatigue management for someone with EDS may include the use of a wheelchair while going outside so that the individual with EDS can have enough energy to cook food for dinner. However, if an outsider is to perceive that the individual with chronic fatigue gets up from their wheelchair to grab something, it is a lot easier to perceive that they are “faking it” than accept that they have a condition that the outsider does not understand. Potential dehumanizing assumptions can then be made about this person with EDS and stigma towards the person with the disability can occur. The ignorance by the outsider can be mended by education and awareness regarding EDS and other conditions where the presence of an invisible disability is possible. This educational and awareness piece will help minimize the amount of stigma towards those that are already dealing with a lot through their disabilities without going through the commitment and energy to disclose what they are dealing with to utter strangers.

Next Steps:

- **Acknowledging and managing these judgements and making people more aware of them when they come up is important to allow a more equitable society.**

Health Care Professionals and Related Care

This Section: Key Points

- **There is limited knowledge regarding EDS and a one size fits all approach does not work.**

EDS is a unique condition that cannot solely be managed by following the standard protocols for treatment. Due to the variability of symptoms and niche healthcare needs, the main basis through each discussion is that there is no one size fits all approach. There is also an evident need for increased knowledge and awareness around methods that has been known to be successful for EDS patients to create expectations for the stakeholders in the healthcare system that are working with people that have EDS symptoms. However, while some methods have been found to work for EDS patients, there also needs to be recognition that, just as EDS presents differently amongst people, treatment may not suit the needs of a new patient arriving with EDS symptoms. Therefore, it is important for healthcare practitioners to provide options, while also empowering individuals with EDS taking an active role within their treatment to understand what works for them and the methods that are suitable to their needs.

Next Steps:

- **Health care providers and stakeholders in the healthcare system needs to acknowledge that there is an active role in the patients' treatment to understand what works for them**

Pain Management

This Section: Key Points

- **A wide range of modalities focused on the patient with EDS needs to be talked about as there are a lot of things that may or may not work for each person**

Pain management strategies can vary in risk and the benefits depending on the modality and the client. Increased knowledge regarding varying pain management techniques for people with EDS is increasingly important. Managing pain and relieving the pain is a critical need for those with EDS and individuals living with chronic pain to be able to effectively perform in their day-to-day activities, thus, improving their quality of life. Client centered care regarding pain management is important to keep considering when a patient with chronic pain and EDS presents to the health-care professional. For the most part, each time that someone with EDS goes to a specialist with a focus on addressing pain, there is a different experience that ensues. There are limited tools and strategies that the health care provider has in their belt. This is further reduced by many factors such as an overlying stigma on prescribing opioids for pain management, abnormal responses to medication by the patient presenting with EDS symptoms, and the overall variability of comorbidities and presentation among people. The methods that work need to be more widespread, accessible, and easily referable for practitioners when needed. This is to make sure that outside of medication, other techniques such as focusing on relaxation, mindfulness, hydrotherapy, EDS focused exercise are made known to patients, so that they can make an informed decision regarding their care, especially as some techniques work better than others for different people. Options around pain management should be made known to the patient outside of the common prescription of pharmacology, physiotherapy, and psychologic interventions.

Additionally, there needs to be more awareness in relation to the barriers and facilitators that make pain management feasible for the individual in their situation and their own accessibility needs.

Next Steps:

- **Increased awareness and knowledge about the non-traditional techniques to provide to patients are important as well.**

Energy Conservation

This Section: Key Points

- **Pacing can be a useful strategy, however remaining client centered in the approach is important.**

One of the most prominent themes with people that have EDS is the idea of energy conservation and pacing. It is hard for people to do the things that they want to do when chronic fatigue is a very common symptom. Pacing is a known strategy that can help to ensure that patients can do what they want to do consistently over time. A common analogy used to put into perspective one’s energy levels is the spoon theory. In this theory, the spoons are analogous to the amount of energy that individuals have in their day, and once they have used up all their spoons, they are no longer able to function in the way that they desire. For example, an individual with EDS may start off with 10 spoons in their day, however, an individual not presenting with a disability may start off with 30 spoons in their day, and thus, have more energy to spend. Additionally, one task such as doing the laundry may take an individual with EDS three spoons, however, for an individual without a disability, it may take one spoon. Thus, the spoon theory is a helpful way for healthcare professionals to conceptualize energy use for those with a disability like EDS, to understand more about how their capacity for work can be different than the person without a disability, and furthermore how to provide the support needed.

Even though pacing is a useful strategy and knowledge about it can be helpful, client centeredness needs to take precedence to support the individual with EDS to achieve the things that they want to do. It is a balance between allowing the client to be able to manage their health and symptoms while also performing all the activities that they want to and are not quite used to forgoing. This can be accomplished through utilizing a consistent pacing strategy or expending one's energy to the maximum, followed by days of recovery. Even if the health care provider believes that pacing is more beneficial, informing the client about their options on where to put their analogous spoons in the day is important. Additionally, it is important for the healthcare provider to acknowledge the client's needs and take a collaborative approach to ensure that the client is safe but is also autonomous within their healthcare in terms of energy conservation.

Next Steps:

- **More consideration and acceptance towards client's decisions regarding how they want to engage in their day-to-day occupations, such that they are given a safe space to make autonomous decisions.**

Sleep Management

This Section: Key Points

- **Sleep is critical to address within the EDS population as it impacts how one functions throughout the day, as well as their symptoms.**

Sleep is a large part of one's day and being able to attain an adequate amount of sleep where people can function throughout the rest of their day is critical. These levels can vary depending on the person and the tasks that they need to perform, however sleep management is a very important area to address for the EDS population. Without adequate sleep, there are various symptoms that can arise that affect cognition, mood, and overall energy throughout the day. Addressing sleep as a part of the way someone presents themselves to the healthcare provider or anyone else is needed. For example, if someone gets two hours of sleep, which can be normal for someone with a connective tissue disorder, their presentation may seem to be more depressed compared to their real baseline. This can cause further problems such as misdiagnoses and gaslighting towards the physical illness that they are experiencing instead of addressing the fact that the quantity or quality of sleep is inadequate. Research and further education and awareness is needed for those with EDS especially for somnologists and sleep doctors. Furthermore, therapists and other healthcare professionals need to acknowledge this and learn ways to address sleep in their therapeutic practice. This can be tied to the amount of energy that people have throughout the rest of their day and what they are able to do. Further links in conjunction with energy conservation techniques need to be addressed and learned about for this population with connective tissue disorders.

Next Steps:

- **Further awareness of different sleep presentations to various healthcare providers especially as it relates to EDS**
- **Further awareness of EDS and connective tissue disorders to sleep doctors and sleep specialists**
- **Further research into sleep management and other symptoms and how it relates to the presentation of the client within EDS**

Physiotherapy Exercises

This Section: Key Points

- **Physiotherapy is an important technique used to help people manage their symptoms with EDS, but can be harmful when it is not tailored towards the needs of EDS.**

Increased knowledge relating to physiotherapy is critical for patients with EDS. Physiotherapy has been expressed as being helpful for both preventive and rehabilitative purposes for many people with EDS. It has been said to help minimize the prevalence of pain, increasing muscle strength to support joints, and decrease overall symptoms, while also helping with overall resilience and increased energy when it goes well. When it goes well is the best-case scenario. Understanding what treatment looks like for people with EDS for physiotherapists is critical because the worst-case scenario can cause harm, especially in the case where the physiotherapist may not be familiar with EDS. The sharing of information amongst physiotherapists and enlightening new physiotherapists about EDS is important to ensure that harm is not being done and that the exercises are modified to be completed in a safe and client-centered manner. Creating an interprofessional collaborative approach so that people with EDS feel safe and comfortable getting the treatment when they need it is important as well. The other aspect to physiotherapy care is the lack of funding available for those with the needs of a patient with EDS. Reducing the barriers and enhancing the facilitators to going to an EDS friendly clinic is just as important to ensure that people with EDS are getting the highest quality care as possible from a team that is knowledgeable about the condition. It is evident that there needs to be increased awareness so that this population can be helped in all stages of their disease. There also needs to be an increased awareness of EDS within the educational systems to promote learning among new healthcare professionals to help people that present with EDS-like symptoms to prevent harm to the patients who present with unique needs.

Next Steps:

- **Safe methods need to be known by physiotherapists so that they can help with treatment for those with EDS**

Neurological Care

This Section: Key Points

- **There is a lack of neurological and neurosurgery care for those with EDS within Canada and there is no support to be able to refer to other countries.**

Neurological care with regards to treating people with EDS is an aspect that has been largely overlooked. Due to the fragility of the different tissues and the niche area required to treat people with connective tissue disorders, there are not any known surgeons in Canada who can treat some of the common comorbidities that present with EDS. The surgeons that are capable to do such surgeries are not willing to without the lack of knowledge and training about the complications involved with people that have EDS. Many surgeons are not willing to touch people that have a high risk of failure because failed surgeries affect the amount they get paid as per the funding model. Thus, due to the lack of knowledge and the high rate of failed surgeries for those with EDS, many surgeons are not willing to perform surgery or even learn the techniques.

For some patients that can, they end up going out of Canada and to the United States to receive surgery. This is completely paid for out of the pocket by the patient and their families because of the lack of availability of specialists that can refer people to get care out of country. Furthermore, if these treatments are not successful, further complications can ensue, and they are ones that the Canadian healthcare system is not prepared to support. Additionally, as it is based on out-of-pocket expenses, there are no legal protections for these patients as well as rehabilitative care post-operation. This presents multiple barriers. First, the patients must have the means to be able to go to another country to receive the care they need. This consists of financial and temporal resources by the patient as well as their support system. These resources are brought in by the patient and they highlight the urgent need for people with EDS and other related neurological conditions to be able to receive the care they need within Canada or to be funded elsewhere.

Next Steps:

- **Readdressing the funding model for surgeons to have incentive to perform surgeries on those with EDS**
- **Increased care for those with EDS post-operatively and relooking at the process to refer people to other countries for care if Canada cannot offer it.**

Occupational Therapy and Mobility Aids

This Section: Key Points

- **Due to lack of awareness, people with EDS like symptoms use devices not made for their purposes and can have barriers in finding ones that suit them best.**
- **There are multiple meanings behind why devices are used or not used.**

Mobility aids and assistive devices can have different meanings for different people. The use of mobility aids can change depending on the purpose. The original purpose of the mobility aid may not suit the best purpose for those that have EDS symptoms. Due to the lack of funding for specific mobility aids catered for the EDS population, much of the assistive technology has different purposes. This presents two major problems. First, there is a large gap between what people with EDS need and what they know exists out there. If every device that can help the EDS population is in a niche marketplace that is not intended for them, searching it out and finding devices for them can be exhausting. Secondly, funding is another barrier to receiving these supports. The mobility aid that is specifically marketed as an ankle brace post-sprain that are bought by people with EDS that present with hypermobile ankles dilutes the need of bracing for the hypermobile population that needs ankle support. As the device is purchased for a specific use as seen by those with EDS, it can be difficult for it to be claimed without challenging it as the purpose stated is not what it is purchased for. Increased knowledge and awareness for devices that suit people with EDS are increasingly important among health care practitioners such as occupational therapists and orthotists so that the custom-made devices are readily available for the people that need them as well as being able to claim the devices even if it is not the intended fabricated purpose of them.

Enhancing this point further among the general population, there is a misconception of the purpose of each assistive device that is used. Different assistive devices can be perceived as inappropriate by the outsider that are not privy to someone's diagnosis of EDS. This can influence what the person is able to do to fit in socially in a safe way. Making sure that there is a climate that is environmentally accessible is very important. This means physical barriers and limitations need to be known and addressed as well as psychological ones that address the judgement and shaming of the presentation of people with disabilities as they try and get through their day. Awareness of the invisible disability and accommodations for the general population can help reduce the stigma behind assistive devices as well as open more compassionate communication between people that do not understand the experiences that individuals with disabilities face.

At the root of most of these issues is the lack of awareness of the needs of those with EDS. Devices that are used for other purposes such as to aid with increased balance for older adults or support for hemiplegia in an acquired brain injury can sometimes be useful for the EDS population. A lot of these devices are thought for those specific groups however, and not for those with hypermobility disorders. For example, walking with a standard walker for the EDS person that has chronic fatigue can be exhausting due to the weight of the device. The use of these devices can also put increase stress on the upper limb and make it difficult to do for long periods of time without dislocating their shoulder. These types of things are not considered in creation of different devices unless it is custom made for specific people.

Next Steps:

- **Increased funding, research, and awareness in regard to mobility aids and assistive devices for the unique set of needs presented by those with EDS.**
- **Awareness around use of mobility aids and assistive devices within the general population ot reduce stigma.**

Nutrition and Diet

This Section: Key Points

- **There is a need for professionals who specialize in nutrition and diet and have awareness for EDS, to help manage unique food restrictions.**

Common comorbidities and conditions such as Mast Cell Activation Syndrome (MCAS) can cause many intolerances to various food which makes eating difficult for those with EDS presenting symptoms to eat. There is heterogeneity between what everyone experiences and the limitations that relate to them. Increased awareness of foods and triggers for the management of complex cases such as the individual with EDS needs to be further explored. This can help provide guidelines for the EDS population that have certain reactions to various foods. There will always be a trial-and-error process to find out what works best however increased structured guidelines and awareness can help support that. Increased knowledge of common triggers for MCAS in relation to EDS can be helpful to minimize what triggers can be mitigated for the client. The other aspect of managing nutrition and diet is having access to those that specialize in these areas such as a nutritionist or dietician. However, because EDS is not well known in the medical community, there are little supports in terms of nutritionists and dieticians who are educated about EDS. Therefore, many individuals are left figuring out on their own what foods work with their body, while putting themselves at risk for the reactions that may present with each food intake.

Next Steps:

- **Encourage education within the following disciplines: Nutritionists, Dietitians, Allergists, and Pharmacists about EDS in relation to MCAS.**
- **Creation of guidelines for individuals with EDS around their diet, and more support on identifying what foods, medications and supplements may cause harm.**

Transportation

Public Transit

This Section: Key Points

- **Accessibility by public transit is difficult to navigate and can be complex for those with disabilities, especially if it is in between different municipalities.**

The transportation services that are available for people with disabilities are not consistent. It is up to the municipal government to fund each service which causes a lack of consistency when moving from one region to another. Due to the heterogeneity in the system that is set out, some municipalities are more easily accessible than others. For the EDS population, there are increased challenges for transportation services. There is a requirement of different documentation needed for accessibility needs. This can include documentation as per a doctor or a physiotherapist which can be difficult to achieve, especially since EDS is not well known, commonly misdiagnosed, and is largely an invisible disability. Furthermore, there are also barriers in getting an accessible transit pass. Due to the differences in municipalities, accessible transit in moving from one district to another is challenging. This is further exacerbated with more rural neighbourhoods as opposed to urban ones. The use of accessibility devices on some transit buses have been neglected as well. Depending on the type of bus and region, large wheelchairs or scooters may not be able to be loaded onto the bus, thus, impacting how individuals with these devices are able to be independent in terms of their mobility in their community. Due to these barriers, individuals are further isolated within their community because they simply do not have the supports to travel. This calls attention to the fact that there needs to be increased consideration around accessibility in public transportation as well as a need for more community supports that can help assist in travel that are accommodating to the various range of assistive devices.

The other issue with accessibility of transportation is the scheduling aspect. This can be difficult for those with disabilities as scheduling usually needs to be done in advance and can have a maximum number of days that can be planned as well. There are also issues with being able to make it to the scheduled stop on time if there are an increased number of symptoms that arise as the driver usually only waits for a limited amount of time and then leaves. A lot of these things are not explicitly stated and are gained through experience by people with disabilities. Overall, there is a lack of support regarding the public transportation system in allowing for independent transportation for those with disabilities. In addition, increased knowledge regarding the supports and how to use them in the most effective way by people with EDS symptoms would allow for more smoother transitions and a more collaborative and holistic approach.

Next Steps:

- **Increased awareness to those with EDS like symptoms of how to navigate the public transportation system is important as well as community supports to help those with disabilities.**

Accessible/Modified Vans

This Section: Key Points

- **Accessible vehicles can be helpful for those with EDS, but many barriers are in the way of people accessing them.**

Individuals with EDS are more likely to receive a formal diagnosis later in their lives. Due to being undiagnosed and presenting with symptoms that most doctors document as "pain" or "anxiety", while ignoring pertinent information, individuals are less likely to meet eligibility criteria for funding and having access to aids. This makes it difficult for individuals to even consider accessible vans due to their other, more important needs taking priority. Additionally, accessible/modified vans to suit those with disabilities are expensive in nature, and may be difficult to find, especially those that are of lower prices. This is unfortunate as having access to a modified van can allow for individuals with EDS to be more independent in their lives. For instance, one can seat themselves without any assistance from others into the front seat of their accessible van, starting from the garage, using built- in automatic ramps, buttons to close and open the trunk, and just a small amount of arm work. Additionally, these vans are big enough to allow for both ones' wheelchair and other members of the family to sit comfortably as well. Modified vans can empower individuals with disabilities to travel on their own and engage in their community without having to rely on their caregivers or other community supports. This is increasingly beneficial when supports cannot be accessed or are limited depending on the individual's location. However, due to external forces, such as lack of secure employment, insufficient support, or limited funding, these specialized vans are not made accessible to individuals who require it. While these vans are more targeted towards individuals with disabilities, one with a disability may be more concerned with how they will pay for their medications, rent, or provide for their family, especially when they are financially constrained, which is common due to the many other expenses that people with EDS symptoms face. Hence, modified vans are not cost-friendly for the EDS population due to the many challenges described. More support around accessing modified vans for individuals with EDS such as increased financial aid focused on transportation is needed. It can also include various means and finding more services that donate or lower the prices of these vehicles. Due to the benefits of these devices for those with EDS and presenting symptoms, there can be an overall increase with quality of life that comes along with this.

Next Steps:

- **Increased funding and programs to purchase these vehicles at a lower rate or financial aid that can help with transportation.**

Finances and Funding

Individual Level

This Section: Key Points

- **There are increased complexities in navigating the system to apply for funding through different governmental aid packages and no guidance to navigate.**

There are a select number of individuals who are lucky enough to have access to a large multitude of financial resources. Most people in the lower or middle income do not have these resources and likely require some assistance from governmental support, especially as various pieces of equipment, private rehabilitation facilities and services can be extremely expensive. Adding that on top of the cost of living also makes living with a disability quite challenging financially. The overall financial expenses that ensue become a larger problem by a lot of issues in finding employment that helps to accommodate the multitude of symptoms and challenges that people with EDS present with. The limited income can be achieved through the various Disability Support Programs as per each province, the Federal Tax Disability Credit and subsidization of different forms of equipment through niche charities and the assistive devices program. Navigation through the system to gain funding for all these expenses with limited income, and benefits poses many challenges, not to mention if there is a disability that limits what people can do. When people are dealing with a chronic disability such as EDS which encompasses decreased energy, chronic pain, and brain fog as general symptoms (as well as multiple others), this makes navigating through the healthcare system even more exhausting. This is exacerbated when EDS is quite underfunded and flies under the radar by government and charitable programs which makes it even more difficult to have support while managing everything else. Furthermore, a diagnosis is necessary to be eligible for many supports, which can take decades to get. The number of challenges to survive to get the funding needed are many and addressing each one is necessary to a more equitable future.

Next Steps:

- **Education to healthcare providers to guide clients to apply for funding or increased roles to help navigate through the complex system that is laid out.**

This Section: Key Points

- **There are issues and gaps with the way that funding is laid out which limits people that have barriers to accessibility within their environment.**

There are limitations to the funding options out there as well. For example, according to the Assistive Devices Program, wheelchairs and assistive devices are not funded if they cannot come into the house. Without funding for these assistive devices, it is more challenging for people with disabilities, including EDS, if they have barriers to enter their home. This can include having stairs to climb, or narrow doorways. Therefore, there needs to be more consideration on the environment that the individual is situated in, so the devices and subsidization for these devices do not become neglected. This example of limitations within the Assistive Device Program illustrates possible gaps that people can have in relation to funding which needs to be addressed.

Next Steps:

- **Increased programs that allow for people that have various barriers to funding to find ways to navigate around those problems.**

Large Scale Funding

This Section: Key Points

- **There are limitations with funding and knowledge for Health Care Providers that can help people with EDS**
- **There are also limited programs to help support people that have EDS or related symptoms and are starting to fall through the cracks of the system.**

For those that have been lucky enough to be able to scrape up the funds, there are more known care providers in the United States that aid those with EDS symptoms and comorbidities such as for neurological surgery or diagnoses. None of these services are funded by the Canadian healthcare system. This is due to a misconception that there are surgeons who can perform the surgeries for patients with EDS in Canada, which have not been done due to the lack of expertise and funding. There are also limitations in the very specialists that would be able to refer to the said American neurosurgeons that are able to treat the complications that people with EDS symptoms endure. There are limits to the procurement by the government in getting a specialist to do the task of treating these patients. There are limited specialists and no pathway to be referred to someone who does have the knowledge and expertise within the country. Therefore, a direct honest pathway in the system for people that need this care needs to occur. It is critical to give people access to the surgeries that they need to live well.

There are limits in terms of charitable organizations due to the lack of awareness and education that can help those with connective tissue disorders. In terms of other funding possibilities, there are limited programs that help people with EDS in Canada. The funding comes from possible other comorbidities and conditions that the patient has which makes it very difficult for people with EDS to get the care that is needed for them because it is not specified to this disease. Further awareness and education need to be implemented on a large scale where programs are willing to fund people that have slipped through the cracks and do not fall into a broadly funded category especially if they do not have a diagnosis, are caught in limbo between appointments and without the access to care to live in a humane quality of life.

Next Steps:

- **More pathways for specialists to collaborate to share knowledge and expertise regarding operation of EDS patients.**
- **More awareness of EDS in regard to large scale funding programs.**

Section 5: Healthcare System Gaps

A. Misdiagnoses

B. Getting Diagnosed

C. EDS Clinic Gaps

D. Challenges After Diagnosis

E. Bias and Stigma

F. Mental Health and Mental Health Supports

G. Client-Centered Care

H. Multidisciplinary Teams

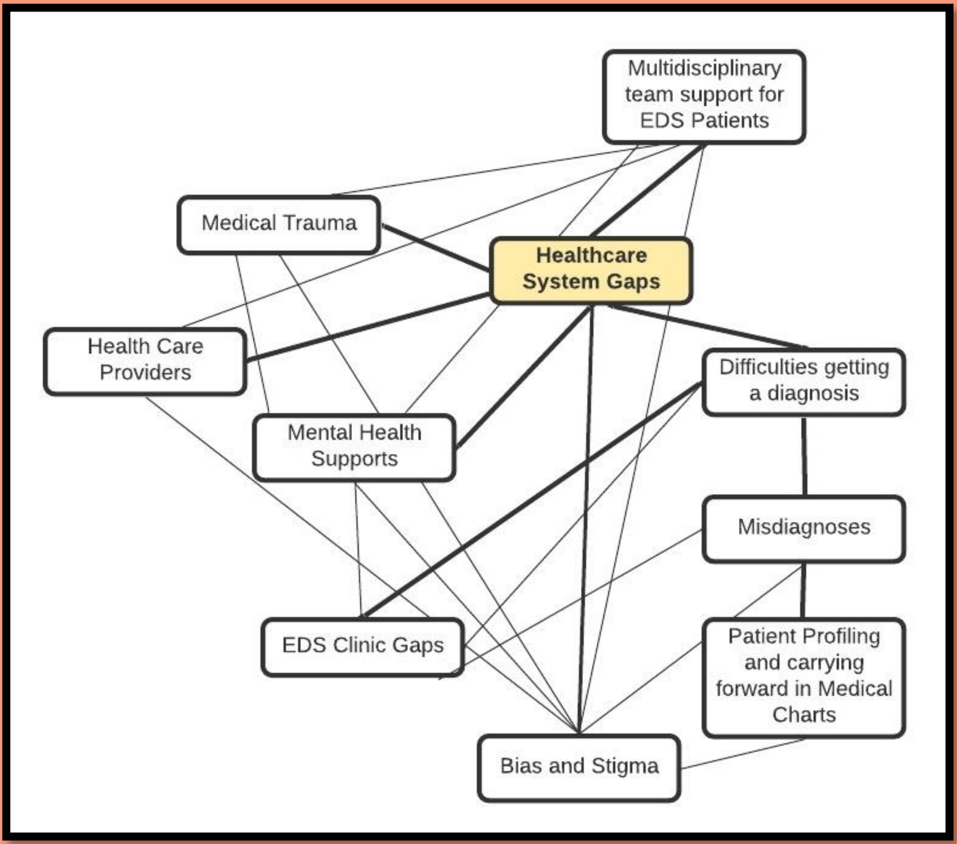

Figure 5: Healthcare System Gaps

Misdiagnoses

This Section: Key Points

- **Misdiagnoses are common due to lack of knowledge which carries biases over into further appointments.**

One of the major gaps in the healthcare system is the lack of knowledge and awareness around EDS and its associated comorbidities that acts as a barrier to the care received by individuals who present with symptoms of EDS. This is something that has been consistent among most aspects of the healthcare system and how people with EDS are treated.

Often, individuals with EDS are misdiagnosed based on insufficient knowledge or investigations into the presenting symptoms. Common misdiagnoses include fibromyalgia, chronic fatigue syndrome, and many mental illnesses, such as bipolar disorder and depression. As a result of these misdiagnoses, patients do not get the sufficient care needed to address their physical symptoms. They are often left feeling confused and invalidated about their experiences due to being dismissed by their healthcare providers. These misdiagnoses get translated through documentation that healthcare providers write up, which do not capture the true nature of what is happening to the patient. As other healthcare providers access these reports, they are only exposed to the surface level knowledge of the misdiagnosis and tend to hold a bias on what is said of the patient in their file. For instance, an individual presenting with EDS symptoms may see a gastroenterologist for their digestive system concerns. However, if simple sentences are written in the patient’s file that describe “anxiety”, “hypochondriac” or “pain”, the healthcare provider may be biased in how they perceive the patient, and thus, may end up dismissing the patient’s concerns completely. As a result, patients are often told, “it’s all in your head” or “if you stop worrying, the symptoms will go away", and a thorough investigation is not completed. This is a problem because medical files are not reflective of what the patient had described, but rather what the healthcare provider perceives, which can cause biases to be carried out into further appointments. This dismissal of the patients leaves them with negative feelings instead of with resources or further steps address their symptoms.

It appears that because EDS patients present with many complex symptoms that do not seem to fit together or have an explanation, many healthcare providers tend to take the easy path to describe what seems to be happening based on words that they do know, again stemming from the fact that they have not heard of or learned about EDS. It is evident that the lack of awareness and education around EDS for these healthcare providers has resulted in many patients feeling as if they have been tossed around the healthcare system, enduring many misdiagnoses, and more often than so, finding themselves fighting against the very system that is said to provide care. Active listening to patients and what they are experiencing is important to be taught and reinforced for all healthcare providers. As per many patient responses and reports, this simple skill can help minimize the dismissiveness that can be done, especially when it is about something that the healthcare provider is unaware of what is happening.

Next Steps:

- **Increased training to health care providers on being receptive and active listening so they can understand what patients are experiencing and provide quality care.**

Getting Diagnosed

This Section: Key Points

- **Due to the complex and variable nature of EDS, diagnosing the disease can be difficult, especially the Hypermobile type where there is a lack of knowledge.**

The path to getting a diagnosis for EDS is just as complex as its symptoms. It is a long journey, from one healthcare provider to the next, each giving different information while at the end there are no answers. EDS presents differently amongst individuals as well as throughout the day. In addition, there are many comorbidities present that make the condition even more complex. As a result, reaching a diagnosis is difficult as there is a thorough lack of understanding behind EDS and what it entails. People are often dismissed until they meet a healthcare provider who is somewhat familiar with the symptoms. Genetic testing can be done for a lot of the subtypes; however, most provide inconclusive results and out of the subtypes, the hypermobile type is the most common, yet there is not a genetic marker, and thus, diagnosis is difficult to reach via this route. The criterion for the hypermobile type is not completely reflective of EDS patients because not all patients will present with hypermobility in all joints or have smooth and stretchy skin which are the most common symptoms. For example, patients may be asked to show their abnormal presentation to demonstrate they do in fact have hypermobile symptoms of EDS, however, depending on the day, or the pain it causes, they may not be able to do it. Through the lack of acknowledgement for the variability, clinicians fail to recognize that EDS patients do not all fit into one box. People presenting with a broad range of EDS symptoms are left feeling humiliated thinking they are finally getting help but are further devalued by clinicians who do not believe the individual because their symptoms do not fit into the very specific criteria for a diagnosis. EDS symptoms are unique, and it is important to acknowledge that while one person may check off all the boxes for hypermobile EDS, it does not mean the next person might, yet they may also have hypermobile EDS. There are many problems with diagnosis of EDS because of its complex nature, and therefore, more research should be invested into the properties of EDS to eliminate these gaps within the current criteria for EDS. Furthermore, there needs to be acknowledgement of the broad range of symptoms on how people with EDS can present as well as increased strategies to manage them.

Next Steps:

- **More research about commonalities between the hypermobile form of EDS as well as the variability of symptoms.**
- **More awareness and education to healthcare providers regarding EDS to allow for proper diagnoses or referrals to occur.**

EDS Clinic Gaps

This Section: Key Points

- **The limitations with the novel EDS Clinic found in North York are outlined as minimal funding, differences in diagnostic criteria, lack of connections to the community and having a gatekeeper.**

The EDS clinic in Ontario has been a development in addressing the needs of the EDS population, however there are still many gaps within this clinic that have presented challenges for many individuals. When individuals are referred to the EDS clinic, they may still face additional challenges related to not being believed about having EDS, which can impact their current diagnosis or stand in their way of getting an official diagnosis. The EDS clinic also has a gatekeeper involved with it which makes it so only people that reach a certain threshold of symptoms can be admitted into it. Especially with the heterogeneity of symptoms, this is not very effective since it neglects the rest of the patients that are experiencing symptoms and challenges that are EDS related and have found it difficult to get care themselves. This means that the patients that do not fulfill the criteria to get in are rejected without help. The EDS clinic has a unique diagnostic criterion than ones that general practitioners would use, which makes it difficult to get a diagnosis from the EDS clinic which is what a lot of people are lacking in the first place. Furthermore, clinicians at the EDS clinic tend to look for hypermobile joints, in which patients are asked to demonstrate their hypermobility and asked to show movements that that may be uncomfortable with. Due to not wanting to get their diagnosis revoked, may patients endure further pain to show the clinicians their hypermobility, which may also result in injury as patients are pushing themselves to be believed. Additionally, due to the various days and presentation of symptoms on the day of the appointment, it provides variable times for assessment. Assessments on days where the individual is having a good day can cause clinicians to overestimate their capabilities. As a result, many individuals have felt humiliated and have not been believed of their symptoms, which can affect the diagnosis that they have. This diagnostic criterion has been shown to be different and more rigorous, which has resulted in some people getting their diagnosis pulled from their charts leaving them in a worse position than when they came in as the accessibility to services get diminished. Finally, the connection to resources after the EDS clinic is not very strong, especially as the awareness is lacking through different rehab centres across Canada. These further limits the number of things that can be done for the patient and makes it more difficult to provide help where needed for those with EDS. Furthermore, the time it takes to get an appointment can range from months to years due to the lack of resources focused within this area. Due to the lack of connections within the community, the gatekeeper, and minimal resources to this clinic, it makes it difficult to provide efficient care for the EDS population. Increased funding for the clinic as well as doctors who can address the large EDS shaped gap in the system would be of benefit. Moreover, increasing education and awareness towards those that can provide services to the EDS population is important as well to allow more referrals and connections for the people that need help.

Next Steps:

- **Being aware of the differences between days and diagnostic criteria is important to provide diagnoses.**
- **Further funding to the government and awareness to the connected communities is important to ensure people are getting the care they need after going to the clinic.**

Challenges After Diagnosis

This Section: Key Points

- **There are challenges even after diagnosis in getting care from connected health care providers as well as the lack of funding of programs.**

One would assume that after getting a diagnosis of EDS, the healthcare journey would seem easier, but a new road of difficulties emerges. Even with an official diagnosis, there are still healthcare providers who refuse to believe it. Moreover, due to the complexity of symptoms, access to care and support is still limited. Specifically, many people with EDS either do not meet criteria for programs, or because EDS is not well known, no programs are available that are tailored around supporting EDS symptoms. Therefore, there are still many barriers experienced around getting the help needed, even with a diagnosis, due to stigma, discrimination, and lack of awareness and education around EDS.

Next Steps:

- **Increased awareness of EDS to health care practitioners and the public are important to provide proper care where needed and reduce stigmatization.**

Bias and Stigma

This Section: Key Points

- **The stigmatization of chronic pain and other symptoms in the health care and the limited access to care for those that require it.**
- **The stigmatization of EDS and unwillingness of doctors to help due to their own fear due to past situations.**

Bias and stigma are still largely present in the medical system, further preventing EDS patients from receiving adequate care. Both chronic and acute pain is a symptom of EDS and gets overlooked in the medical system. Upon hearing the word pain, healthcare providers tend to undermine the pain experience, and put labels on pain patients. From the patient perspective, many have described practitioners providing minimal care and that their concerns of pain were psychological rather than physical symptoms. Furthermore, individuals who come with pain concerns can be labelled as drug seekers, which prevents patients from getting certain pain medications such as opioids. This is further exacerbated by the abnormal metabolism of these drugs by those with EDS. Each drug is different and affects people differently, however a common theme has been that those with EDS metabolize these drugs differently which needs to be considered while taking them. This reinforces the stigma behind it and makes it more challenging for health care providers and patients to tease out when pain medication is needed versus when it is not. Due to this bias, individuals with EDS symptoms may not access healthcare because they feel they will be turned away based on past experiences in managing these symptoms. For instance, many individuals with EDS symptoms described having to wait until one’s situation is in the worst possible state before going to emergency due to the fears of being rejected and improper care because of the perceived lack of seriousness of the symptoms by previous healthcare providers. When they get to this point, it makes it more difficult because there is an increased need for advocacy for their symptoms, especially in an emergency. Moreover, many individuals have also described that they have weaned themselves from many pain medications or no longer want pharmacological treatments because without the list of those medications on file, their chance of getting better care is increased, and they will no longer be seen as a drug addict. It is evident that this stigma and discrimination towards drug addictions has prevented many pain patients, especially those with EDS symptoms, from getting the help they need. There needs to be an increase in support for those with drug seeking behaviours who do come into the emergency department of the hospital, as well as how to approach situations where patients come with concerns of pain. The opioid crisis and policies created have also put healthcare providers in a back corner regarding prescribing opioids for pain management. There are fears of having licenses revoked or endangering lives if one were to prescribe opioids for a patient with pain concerns. These problems stem from the government level around inadequate policies, lack of awareness, and lack of evidence-based approaches to addressing this situation. Individuals with EDS presenting with chronic pain require more pharmacological access to help them manage their pain. In their experiences with the pain, they are unable to engage in their daily activities, and due to the lack of support, their quality of life is significantly reduced. More attention is needed to help modify policies and management around opioid use to help eliminate stigma and discrimination and to allow for healthcare providers to feel more secure and confident helping pain patients. An increased awareness of these biases and knowledge about chronic pain and its relation to those with EDS is crucial.

There is also the stigma behind having an EDS diagnosis on its own. Due to the lack of treatment and the negativity experienced by those that have had this condition, it does show up on the news sometimes where there is a shame and problematic treatment to some doctors and healthcare providers. Due to this, the response by healthcare providers is that they are fearful to treat patients with a diagnosis of EDS. Along with the uncertain amount of knowledge that is out there, the level of confidence that the average healthcare practitioner has regarding those with EDS is quite low. This is especially certain when the consequences of this means that there is a possibility of being badmouthed by the news and potentially losing their job or having their licence taken away. Increased knowledge regarding EDS and what can be done to manage it is important, along with the systems being in place so that people do not feel desperate enough to shame the doctors to get the care they need.

Next Steps:

- **Increasing awareness to decrease stigmatization in the healthcare industry.**
- **Increased care and confidence in the prescription of medications and other pain management techniques for people with EDS.**

Mental Health and Mental Health Supports

This Section: Key Points

- **When not understanding symptoms, healthcare providers can attribute them to mental health disorders.**
- **Fear of disclosure to health care professionals regarding their mental health is common among EDS patients.**

Mental health is another area of concern for patients with EDS, that is poorly understood in the medical system. As mentioned throughout this report, many patients presenting with EDS symptoms are told, “it’s all in your head”, “it’s just anxiety” or “it could be worse” by many healthcare providers. This repeated exposure to not being believed by healthcare professionals and indirectly made to feel that their experiences are invalid, negatively impacts one mental health. Gaslighting from the medical community to this patient population may result in individuals internalizing these feelings, and blaming themselves for all their symptoms, further damaging their mental health. Individuals have expressed that they have felt mental illness has been used as a weapon by many healthcare providers to explain their behaviours. This has been done without acknowledgement or validation of the patients’ physical symptoms, and the blame is put on mental health issues as opposed to the root cause. It is evident that more awareness is required around EDS and increased exposure to being taught about listening to the patients’ subjective experience, acknowledging it, and taking it as their truth prior to dismissing it as a mental illness.

While those with EDS-like symptoms do have physical symptoms that need to be acknowledged as such as opposed to a (mis)diagnosed mental illness, it does not mean that mental health in general should be ignored. Many EDS patients have gone through the medical system feeling abused and traumatized due to the lack of quality care for those experiencing connective tissue disorders and subsequent medical trauma can ensue. This can present in a form of post-traumatic stress disorder and can have severe consequences to one's mental health. Additionally, many individuals with EDS have felt that they are unable to be truly honest about their mental health status and have learned to lie from a young age about their mental health. Many individuals have described that they feared that their physical symptoms would be further ignored and invalidated if they shared their concerns with their healthcare provider. Thus, from a young age, mental health and therapy supports are not provided because of these internalized and valid fears of not being believed. This presents another unique challenge to get people that are dealing with a multitude of symptoms to access care as they rightfully are scared to see healthcare practitioners. Due to ignorance around mental health and awareness of EDS, health care for this patient population is insufficient. There is limited support to aid in addressing these fears presented by the individual. Increased support to work through these negative experiences are needed by the healthcare system, especially when they are the ones that are causing it. Specifically, there needs to be more specialists in the disciple of psychology who specialize in understanding the impacts of chronic pain, medical system post-traumatic stress disorder and have awareness of EDS to provide patients the resources and tools needed to manage their health and well-being. There is also a need for training and education around understanding that people can have mental health conditions that are not attributed to their medical conditions, and to acknowledge both domains on the health and well-being spectrum.

Next Steps:

- **Education around checking biases when there are misunderstandings of disorders and dismissing symptoms if they are not understood.**
- **Acknowledgement of the fear to disclose information to healthcare providers and education for trauma informed care and other modalities.**

Client-Centered Care

This Section: Key Points

- **Patients do not feel dismissed when they are shown empathy and active listening by the healthcare provider.**
- **Miscommunications between the patient and the provider due to overwhelming symptoms and dismissal based on presentation of the patient.**

While ignorance of EDS has been a prominent theme at the basis of many of these issues, one big concern of this population is the number of times they have not felt listened to by their healthcare providers. It is important to actively listen, and display empathy in any patient encounter to enhance the experience of care for the patient, which also helps the healthcare provider understand more about the patient's concerns. Individuals with EDS have strongly stated that what they really wanted was for their healthcare provider to listen, to inquire more about their symptoms, be open to learning, creating a safe, non-judgemental space, and to not abandon them through this process.

The lack of communication between both provider and patient has also been a factor in insufficient care. Those presenting with EDS symptoms often have difficulty communicating with their healthcare providers due to consistently being dismissed and trauma experienced by the medical system. In addition, because there are many concerns, patients come to appointments not knowing how to discuss their symptoms in a way that is not overwhelming to the healthcare provider. The information overload can result in the negative behaviours presented by healthcare providers. Healthcare providers may also not know how to interact with patients who come with overwhelming concerns. The lack of awareness and education around EDS causes healthcare providers to be unaware of how to support EDS patients. Although there are no known treatments, lack of communication has presented to be a large barrier in receiving the care needed. Therefore, there needs to be more research and practical implications around developing communication guidelines for both healthcare providers and those with EDS, such that appointments are effective and meets all stakeholders needs to the best of abilities. A common thought among health care providers and patients alike to smooth out the communication has been the need for patient advocates within the medical community. This can help make appointments effective and create links to resources to support people that also present with a multitude of symptoms. Further research and practical implications of a project such as this is needed for patients to feel heard and understood in their appointments.

Next Steps:

- **Creation of possible communication guidelines for patients and healthcare practitioners.**
- **Patient advocacy project to help patients navigate the system and break down the important information for doctors when needed.**

Multidisciplinary Teams

This Section: Key Points

- **There are very niche specialists that take into consideration different body parts which can hinder communication among healthcare providers.**

The creation of a multidisciplinary team targeted towards supporting the EDS population is also a recognized need. EDS presents with symptoms that range from one body system to the next, and therefore, individuals require a team who will collaborate, and take a whole-body approach to treatment throughout all stages of care. Often individuals with EDS symptoms are seeing specialist to specialist and must act as a mediator within all their healthcare providers, which is both energy consuming, and stressful for one individual to manage alone. Additionally, a lack of communication between healthcare practitioners can negatively impact the patient's care as information may not be effectively translated in the patient's health history. Therefore, it is evident that there needs to be a creation of multidisciplinary teams within the healthcare system that can collaborate and communicate more effectively to effectively support the EDS population and their unique needs.

Next Steps:

- **Increased communication methods between teams or the creation of interdisciplinary teams that cover many different areas and communicate effectively together to support the EDS population.**

Section 6: Social Support Gaps

A. Social/Community Support

B. Family and Friend Support

C. Being a Parent with EDS

D. Being a Parent to a Child with EDS

E. Support Groups

F. Relationships and Dating

G. Dealing with Loss and Acceptance

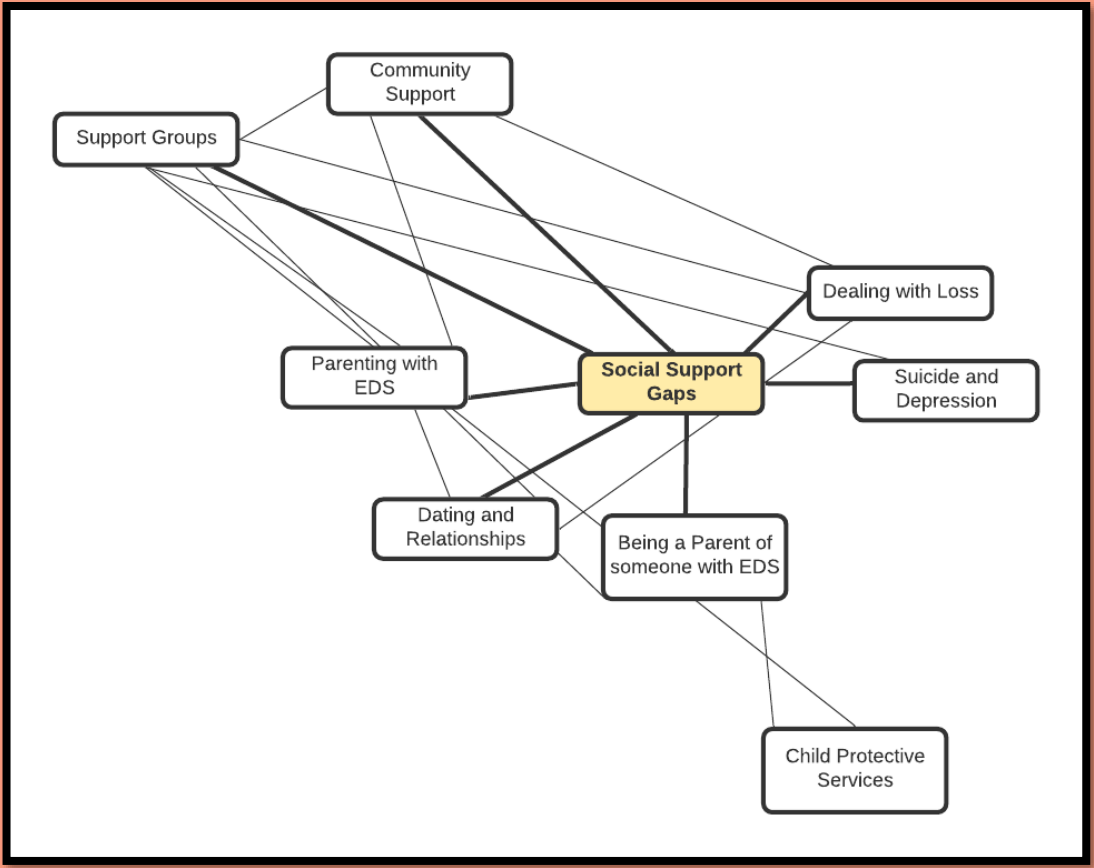

Figure 6: Social Support Gaps

Social/Community Support

This Section: Key Points

- **The importance of support within the community and creating of connections from likeminded members.**

Community support and a sense of identity and belonging as it relates to the disease of EDS is important for increased development of the client's identity and to gain access to services that aid in management of the disease. Especially without the lack of support from the healthcare system, support from other people that are dealing with similar experiences are important to learn techniques that have worked and to gain experience in navigating through the system that has been pitted against this population. The necessity of this support is critical to determine the gaps in the system and to understand how people can manage the challenges they have faced. Furthermore, the connection to resources is critical to be able to survive and thrive so that people can grow within the community in ways that they see are valuable. Support groups not only allow for increased knowledge and resources, but it also allows individuals with EDS to connect emotionally through their experiences, that cannot be otherwise met from others within the support network that do not have the disease. This connection is valuable and increases resiliency in individuals simply by knowing that they are not alone.

The ILC Charitable Foundation has been key in the connection of resources from one aspect to another, being able to connect people to others in similar situations as well as aid through navigating in the system. There are a great number of gaps that the ILC Charitable Foundation has been able to fill that allow for people with EDS to live a higher quality of life. Increased community support and guidance regarding different aspects of the disease is important. These resources are critical to allow for people to thrive while dealing with this disease and needs to be supported by government programs.

Next Steps:

- **More places for people to connect such as support groups and connections of likeminded people who have similar experiences.**
- **Increased awareness and assessments of needs to fill the gaps within the system.**

Family and Friend Support

This Section: Key Points

- **Having family and friend support is important to maintain healthy relationships.**
- **Feelings of isolation and ostracization is prominent with those that have EDS especially when their family does not understand the condition prior to diagnosis.**

A common theme that has been prominent for those that have EDS is about the personal social support system that is in place. The people that are important in these clients' lives is an important factor in the amount of support that they have. Due to the EDS and its' presenting symptoms, there are more differences in experiences in the patients support system, especially as they start to come up. This can cause an isolating feeling for those that are managing the symptoms. Although no one's experiences are the same, the presence of a complex, invisible and chronic disability has the potential to build walls among family and friends. It is important to acknowledge that and be able to understand the different experiences that people have regarding EDS or other undiagnosed connective tissue diseases.

Support from friends and family are critical to be able to manage and cope with chronic disabilities such as EDS. Unless others in the family have lived experience in similar situations, they never know quite what the client is dealing with and vice-versa. The openness and willingness to support the person with EDS or related symptoms is important for people who live with the disability to have a higher quality of life. This can mean in many aspects; emotional, financial, physical or others. Commonly among members, having symptoms or a diagnosis of a connective tissue disorder shows them who they can count on for support when needed. Moreover, when that support is not there or has shifted towards the spectrum of abuse, isolation, ostracization and loneliness, this further exacerbates the problems and symptoms presented by those with symptoms of EDS.

When understanding a complex and chronic disease such as EDS, addressing it in a holistic way involves the family support as well. Addressing the carer and support roles for helping those with EDS is important to ensure that there is a well-oiled system in place. This is important to prevent possible burnout for the support system and finding ways to allow the affected groups to maintain healthy relationships even in the face of the symptoms and comorbidities of EDS. This means providing support for both client and support system, even prior to a diagnosis so that there is a level of belief within the healthcare system that helps validate the patient with EDSs' symptoms.

Further education, awareness and support in a client centered way are needed to help those that are close with and are a part of the affected person directly to make sure that the patient with EDS can feel seen and heard. Even without a diagnosis, understanding how those can be supported that deal with a condition like this can help.

Next Steps:

- **Helping the support system understand what the person with EDS is going through via guidelines or other modalities that emphasizes empathetic listening and validation.**
- **Methods to bring awareness to EDS to allow validation by the support system to occur prior to being confirmed diagnosed by healthcare providers.**

Being a Parent with EDS

This Section: Key Points

- **There are challenges in being a parent on top of having a condition such as EDS.**

Parenting a child in any condition can be difficult. Being a parent, while managing symptoms of EDS and other comorbidities makes it even more challenging. For the parent, there needs to be a balance between being able to care for their child, while also being able to take care of themselves. Due to the lack of awareness of a complex chronic condition like EDS, by the child, the parent needs to be aware for both parties. Consistent mindfulness of what the parent needs to do in their day and within their limitations is important, so that the child can be nurtured without exacerbating the symptoms of EDS. Factors such as the amount of lifting, extreme fatigue as well as chronic pain can all pose challenges involved with parenting. Addressing these challenges while also addressing the symptoms of EDS can be difficult to do, and usually means that support is necessary. Support and connections to various resources would be of benefit to allow the family to better manage the childcare, as well as ensuring that both the parent with EDS and the child can develop healthily. Additionally, with increased supports, the parent with EDS will also be able to develop a healthy relationship with their child and maintain a healthy relationship with their spouse.

Next Steps:

- **Support for those with EDS is necessary regarding childcare to mitigate risks of injury and promote healthy growth and development.**

Being a Parent to a Child with EDS

This Section: Key Points

- **Children can also be disbelieved regarding their pain and it can make it difficult for them to trust people to talk about their symptoms afterward.**
- **Parenting a child with EDS is difficult when they are being told that their child's symptoms are normal.**
- **Parents having their child with EDS away because of EDS symptoms is a common occurrence.**

There are many misdiagnoses that are carried throughout one's healthcare journey, and it takes a long time for people to be diagnosed with EDS or connective tissue disorders. The symptoms that are seen by those with EDS can inhibit general occupations that the child engages in and can limit development. Expressing these symptoms at a young age can cause increased dismissiveness, especially by children. For example, an increased amount of chronic pain can cause dismissive or disbelieved reactions from those in power, such as teachers, parents, or doctors if they do not understand what is going on, which can influence how the child will present with their pain in the future. A common theme has emerged of people not being listened to when speaking about their pain since as a child, they were unable to express it safely. Other symptoms such as vascular issues and chronic fatigue can range from children not being able to keep up with others their own age to possibly having a much more serious medical concern. Increased disbelieving by healthcare providers and those in power minimizes the symptoms that the child experiences' and makes it even more difficult to manage in the future.

Being a parent of a child that has these symptoms can also be challenging. It makes it difficult to parent a child with EDS because of the lack of support in navigating through the system as well as possible stigmatization and labelling of the child. It is up to the parent to help their child in understanding their disease, however that is difficult when they are told by various healthcare providers that there is nothing abnormal. This gaslighting effect can deteriorate the trust parents have in the medical system. Being able to understand what is going on can be difficult, especially if the parent has not experienced it themselves. This can make it hard for people with EDS to get the support they need when they are developing and can be further influenced by the parents. If the parent has EDS as well due to the genetic variation in the disorder, increased challenges can ensue. This can make it difficult to be an advocate and parent for their child as well as taking care of their own health. Due to the lack of awareness and long time to diagnose as well as possible symptoms themselves, it is difficult for parents to support their children through the process of getting the help they need.

Hypermobility in combination with sensitive skin tissues has its own set of issues that it can present. One of the major themes that has come up has been the associated injuries that come about due to these symptoms. Sprains, strains, bruising and dislocations together presents as a red flag for child abuse to the average health care provider. Child abuse is a very serious issue that needs to be addressed. Unfortunately, once a child is taken away from their family by the respective services, fighting to get the child back and disproving the allegations are extremely difficult to do especially with an undiagnosed, invisible condition such as EDS. This can be exacerbated by any potential EDS-like symptoms that the parent is dealing with as there is a large genetic component to it. Furthermore, if they have been lucky enough to regain their child again, both the parent and the child have the fear of it happening again and justifiably would not feel safe within the medical community. This is even more distressing for parents to deal with as the child requires medical support for their EDS symptoms.

The trauma that ensues where abuse does not exist is immense and being able to prevent such an incident is critical. Teasing out where abuse is happening and the multitude of hypermobility disorders is a huge challenge especially if they do co-exist together, however basic awareness of what EDS looks like via hypermobile joints and the varieties of skin presentations is important for health care practitioners to know. The more information the better, however if it is not a database of information, being aware of quick assessments of hypermobility and what EDS looks like is essential and needs to be widespread within the medical community. The consequences of a mistake can cause families to be shattered, especially while trying to cope and understand the disability that the people in their family is experiencing.

Next Steps:

- **Awareness regarding EDS among healthcare providers especially as it relates to children is important.**
- **Support and advocacy for parents in understanding EDS is important especially when it can affect their child.**
- **Increased awareness of EDS among healthcare practioners is important to help prevent false allegations of child abuse.**

Support Groups

This Section: Key Points

- **Support groups are helpful to learn, understand and connect with others however they can turn negative quickly when there are many negative emotions wanting to be heard.**

Support groups are critical to be able to manage a system that has not been supportive to those with EDS and other complex and chronic conditions. It is key to be able to manage and connect to the appropriate resources, where necessary. However, there can be a downside to support groups that can negatively impact health and well-being of individuals who are a part of those groups. The support system through closed groups has the potential to spin out in a negative loop which focuses on the issues that each individual living with EDS has been dealing with in a non-productive manner. Since many individuals with EDS have experienced consistent problems with their healthcare providers who have not shown empathetic listening and are dismissive of the symptoms of EDS, there is a human need to express oneself to others and be heard, understood, and accepted. This is emphasized by the lack of support from the family and friends due to the lack of information behind EDS and possible feelings of otherness that are felt by their closest support. Expression of these emotions that people have and need to be attended to with empathy and compassion are then reliant on support groups. The result is people that are suffering are looking for a way to express themselves and can take different forms. This suffering can be expressed by competitions between people who have it worse, and a search for empathy through people that are reading and listening through the support groups. Inherently, this is not a bad thing; it is simply an expression of not being heard or understood by others that are supposed to provide the help required. Increased support to cope with these emotions are necessary, however negative loops on online platforms and within support groups can create an even more toxic environment. It can cause people to take on the emotional burden due to hearing the negativity that others are dealing with instead of safely unloading their own. One of the ways that have been talked about and have worked in some specific groups to manage this type of environment is through moderators and facilitators to guide the conversation away from the negativity and towards productive conversation focused on possibilities, emotional support, and solutions instead.

Next Steps:

- **More need for emotional support for those who are not feeling heard to safely unload.**
- **Increased moderators to ensure productive conversation via online platforms and support groups are needed to let everyone feel supported without spinning into the anxiety of other individuals' problems.**

Relationships and Dating

This Section: Key Points

- **Dating can be hard for people living with EDS due to stigma, time of disclosure and misunderstandings between partners.**

Dating other people and being able to put yourself out there is a challenge for most people outside of the EDS community. Within the EDS population, there is an increased number of difficulties with navigating through the dating world. Due to the nature of many aspects of disability being invisible, there are challenges in bringing it to the forefront of relationships and knowing how and when to disclose this information.

Many people have been able to date in a non-hindered sense, however having EDS-like symptoms and conditions, brings new challenges to the relationship that others without the disease may not understand. Specifically, there are difficulties from the partner point of view in being able to see the individual as more than their chronic illness, which further impacts how the relationship develops. Additionally, those with EDS may not understand what their partner is going through and may have difficulties in communication to address the problems faced. Moreover, an individual with EDS may feel that their partner is unable to see past their condition and acknowledge the other aspects of their identity that they have to offer, and often experience patterns in their relationship such that their partner starts to slowly pull away when they realize what is happening. Due to a lack of understanding around disabilities, partners may end up with the perception of having caregiver fatigue without living with the person with EDS. These experiences may be common for individuals with a disability trying to find a companion, as they are looking to share an intimate relationship with someone. These challenges may arise due to a lack of knowing how to communicate and understand the perspectives on both individuals involved in the relationship.

Time for disclosure to their respective partner is one thing that is difficult to gauge especially when what each person looks for can vary. Since EDS is a chronic and complex condition, the interaction between partners can influence how the relationship grows. The stigma throughout the social relationships is evident as well due to the ableist viewpoint that influences the dating pool with relationships. Addressing this to allow people with EDS to be able to disclose what they need to their partners can help eliminate stigma, thus, the relationship can grow in ways that both parties wish. People with EDS, or other disabilities may also find it difficult to even date in general due to the effort required in dating as well as the emotional risk involved. Information in this section is from the perspective of those living with EDS and therefore an increased discussion regarding relationships involving more people with EDS, their partners and support system would be beneficial for a more comprehensive need.

It is evident that there needs to be more support for individuals with disabilities like EDS, and their partners in relation to understanding differing perspectives, and working through the challenges and emotional aspects related to this disease and maintaining a relationship.

Next Steps:

- **Further understanding and support of people with EDS and how it affects their romantic relationships.**
- **A comprehensive view of resources available for dating for people with disabilities as well as awareness regarding it.**

Dealing with Loss and Acceptance

This Section: Key Points

- **There are limited supports for dealing with loss, but coping techniques are necessary to manage.**
- **Acceptance of their disability is needed for people living with chronic, complex disabilities like EDS.**

Loss is a reality for everyone. In some form or another, there are abilities that are lost through the passage of time when living with a chronic condition like EDS. These losses can include relationships, abilities, or identities. Being able to cope and understand how to manage and accept that loss is important for the individual. Interventions that target the coping of all the negativity and loss is important to address. Through the multiple methods via social connection, psychotherapeutic techniques or healthy coping mechanisms, there is a profound need for people with disabilities, especially those with EDS-like symptoms to be able to manage. This loss needs to be understood by people living with EDS throughout their healthcare journey. Supports available to help them through this time of loss would be helpful to allow them to begin to accept it. Supports to be able to manage the psychological effects of losing abilities, or people close to the individual are important and are increasingly needed especially in the medical system where it is currently not directly acknowledged.

Acceptance is another concept that has been difficult for individuals living with EDS. Many individuals have described that prior to the flare up of symptoms, they were able to live life in the way they wanted and how they wanted to. However, as symptoms started progressing, losses occur in all areas of one’s health and well-being, thus impacting one’s quality of life.

Individuals with EDS, as described, are in the face of many challenges, and one big issue that tends to get overlooked is the lack of support around helping one to come to acceptance of these changes in their lives. There needs to be increased support and acknowledgment around life with a disability. Just because an individual has a chronic disability, like EDS, they can still live life in the way they want, and how they want to. Attention and support for individuals with disabilities to pursue their goals, which can be done through increasing education and awareness, are needed to allow people to accept themselves and their EDS. By being more open to this conversation and creating these changes at a societal level, individuals experiencing EDS can understand acceptance and manage the losses that happen through the necessary supports by their side.

Next Steps:

- **Increasing awareness for the lack of support around loss and acceptance in the healthcare system.**
- **Providing tools to those that are experiencing loss to shift closer to acceptance.**

Suicide and Depression

This Section: Key Points

- **Suicide is more prevalent in those with EDS especially when they are neglected in the medical system.**

Suicide and depressive symptoms have been reported to be common in the EDS population. The increased amounts of negative emotions such as loneliness, ostracization and lack of belonging may be one of the reasons as to why suicidal thoughts, ideations and the act of suicide are unfortunately, common. The results of constant gaslighting makes it extremely hard for people with EDS-like symptoms to have acknowledgement of what is going on in their physical body, separate from their mental health. As mentioned in the sections above, it is evident that there is a lack of support and care for the EDS population, which can drive individuals into a corner, feeling hopeless, and like they have no other choices.

This is a serious issue and goes to show how many changes need to be made so that situations like this can be prevented, especially through more education and awareness around EDS. Continuous understanding of what these patients are going through by active listening, trusting, and believing in their story can help prevent this correlation.

Next Steps:

- **Promotion of active listening, believing, and trusting in their story is important.**

Section 7: COVID-19

A. Concerns with the Vaccine

B. Access to Healthcare

C. Social Isolation

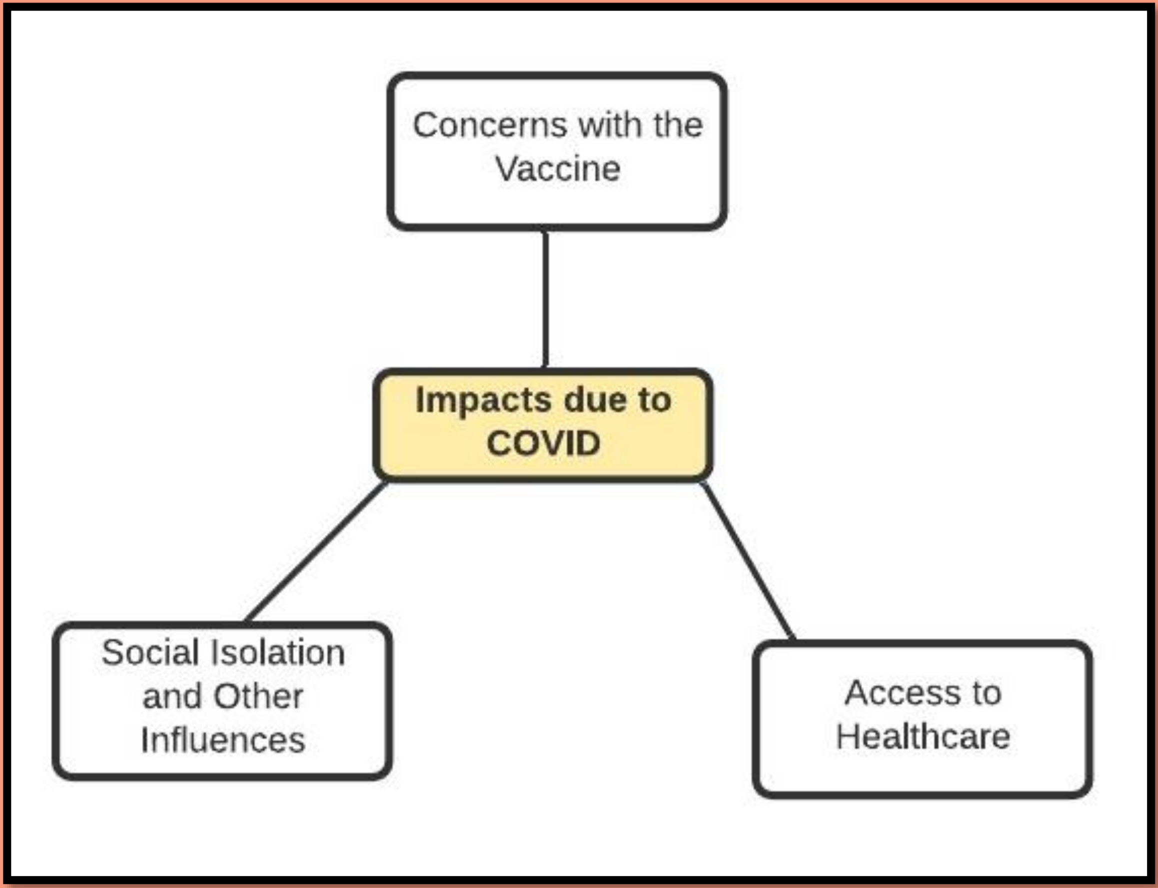

Figure 7: Impacts due to COVID

Concerns with the Vaccine

This Section: Key Points

- **There are increased uncertainties with vaccines, COVID-19, and EDS especially as they are a high-risk population.**

The COVID-19 pandemic has caused multiple public health restrictions that have echoed throughout society. This has ranged from practicing physical distancing among non-household members to limited social interactions outside of virtual or auditory platforms. On top of this the overlaying fear across society has been influential upon others. For those that have chronic diseases such as EDS, an increased number of challenges have ensued.

Individuals have expressed their concerns with the COVID-19 vaccination. Specifically, few individuals have expressed fear with how they may react with the vaccine, due to Mast Cell Activation Syndrome, a common comorbidity of EDS. Thus, due to having a rare condition, there is a lack of research on how the COVID vaccine will react with their body and cells, causing uncertainties with being vaccinated for some individuals. Therefore, individuals need access to more information about the vaccine in relation to high-risk populations, like rare disorders as they emerge. Platforms such as the ILC Charitable Foundation can provide individuals with reliable resources about COVID-19 on their website so that individuals have more access to new research involving vaccinations.

Next Steps:

- **Increased research regarding EDS and vaccinations are needed that other interactions with the comorbidities that accompany EDS are not affected.**

Access to Healthcare

This Section: Key Points

- **Access to healthcare has been very situational with some benefits and downsides to the changes in the COVID-19 pandemic.**

COVID-19 has also resulted in many individuals with EDS putting their health on the back seat. Many individuals have expressed that they do not want to reach out to their healthcare providers because they know how overwhelmed they are with the current situation and the stress that the pandemic has brought on the world. Additionally, some individuals have felt that their problems are minor in comparison to those suffering with COVID-19. In contrast, some individuals have also described that because of COVID-19, their healthcare providers have abruptly stopped follow-up from the last appointments or have not made any progress in putting in referrals. In this case, individuals have described that their healthcare had simply been “frozen”. While some individuals have felt that COVID-19 had limited their access to healthcare, others have expressed that healthcare had been more accessible through the option of telemedicine. This has allowed individuals to quickly get refills for their medication, as well as getting to speak to healthcare professionals from the comfort of their own homes by telephone or virtual platforms which has greatly helped in terms of energy conservation. As such, COVID-19 has brought to light that other ways of accessibility to healthcare can be made possible, such as telemedicine, and should continue to be provided to accommodate for all individuals moving forward.

Next Steps:

- **Continuing to be able to accommodate patients when getting to appointments are not feasible even after the COVID-19 pandemic is important**
- **Increasing supports to manage the COVID-19 pandemic for healthcare providers to continue to help patients and provide adequate support as well.**

Social Isolation and Other Influences

This Section: Key Points

- **Social Isolation due to COVID-19 has made it difficult for those with EDS or has not affected them at all.**

Social isolation during COVID-19 has become a common experience in the world, however, for those with chronic illnesses, like EDS, social isolation has either become worse or stayed the same. Some individuals have described that the restrictions have caused them to participate less in society, even more so than before, as many programs have been closed. Thus, many meaningful activities have been put to a pause because of COVID-19. Furthermore, there are also limited number of facilities that are open to the public as well. For example, hydrotherapy is a commonly used pain management technique, however due to the COVID-19 pandemic, pools have had to close, and it is no longer an option.

While some individuals have felt that social isolation has decreased their health and well-being, others have described they have not been affected as much because this is what their life had been like prior to the pandemic. For example, those with EDS are often unemployed and are at home most of the time. For those who may not understand the aspects of disability, many may view not working and being at home a luxury. However, COVID-19 has shown the world how crucial working has been to their lives. While a week of no work may have been enjoyable, as weeks turned into months, some people's mental health has been negatively impacted. As such, without work, mirrors the experience of some of those with chronic illnesses, like EDS, who are unable to commit to a career because of their health, and majority of their time is spent at home. Additionally, there are less supports in the community for those presenting with EDS symptoms as they may not meet the criteria for programs, or because of insufficient healthcare and poor management, they do not have energy to invest in other activities outside of their homes. Thus, it has been described by some individuals that they have always been experiencing social isolation, and for them COVID-19 has not impacted this area of their life compared to the rest of the world’s experience. In contrast, there are also a group of individuals who believe that changes COVID-19 had brought has helped them shift towards connecting with others using online platforms. Additionally, this has made it easier to speak with others as everyone else is at home as well.

Next Steps:

- **Further supports regarding social isolation for those living with EDS are needed to combat the COVID-19 pandemic, as well as for these supports to continue forward after the pandemic as well.**

Section 8: Further Recommendations

A. Education and Awareness about EDS within the Community

B. Education and Awareness for Healthcare Providers

C. Education and Awareness for Institutions and the Government

D. Education and Awareness for Facilitating Support Groups

E. Further Research Opportunities for Individuals with EDS

Education and Awareness about EDS within the Community

Awareness and education on a wide scale is important so that the public is aware of EDS and the implications that it has for those that it affects. Increased awareness to the public is needed. The main areas to focus on include:

- **Education and supporting those with EDS in the community by allowing them to be connected in their community**
- **Increased awareness of different mobility aids and invisible disabilities within the community**
- **Education to the family and friends of those with EDS and connections with like-minded people**

Education and Awareness for Healthcare Providers

A large gap found has been among education, awareness and programs are needed for the healthcare professionals that work with those with EDS. Further areas to address for healthcare professionals are:

- **Emphasis on active listening and showing empathy to patients, especially about invisible disabilities**
- **Education regarding trauma informed care and acknowledgement of possible traumatic experiences by the medical system**
- **Checking biases of the healthcare provider, and creating collaborative interactions aimed at client-centered care**
- **Training on treating and management of symptoms of those with EDS in each specialty which include and are not limited to**
    - **General Practitioners**
    - **Specialists, including neurosurgeons**
    - **Pediatric and Emergency Healthcare Providers - specifically about Child Abuse and EDS**
    - **Social Workers**
    - **Physiotherapists**
    - **Occupational Therapists**
    - **Nutritionists**
    - **Dietitians**
    - **Allergists**
    - **Pharmacists**
    - **Orthotists**

- **Training healthcare providers about navigating through the system to address the needs of the patient**
- **Bringing awareness to those with invisible symptoms and disabilities and the biases associated with it to prevent patient profiling**
- **Promoting the awareness for the need of medical aids, braces and other devices that can help those with EDS**
- **Continued accommodations towards telemedicine and other modalities, post COVID-19**

Education and Awareness for Institutions and the Government

Addressing the complexities of the healthcare system sometimes requires advocacy towards governmental and institutional systems. The focus on these include:

- **Equitable distributions of power across the government and institutions that create policies regarding those with EDS, other disabilities, and marginalized groups**
- **Increased funding to address the gaps seen with the EDS Clinic and acknowledgement of heterogeneity of symptoms among people and days**
- **Increasing mental health supports to address:**
    - **Medical Trauma (which needs to be a team outside of the current treatment organization)**
    - **Loss and grief experienced through the healthcare system**
    - **Correlation between suicide and the EDS Population**
    - **Support regarding loneliness and the COVID-19 Pandemic**
- **Addressing the gaps in neurosurgery care for those with EDS which includes addressing the funding model so surgeons are willing to perform surgery and creating a pathway for patients with EDS to get neurological care**
- **Focusing on transition of care of youth to adults with chronic and complex conditions**
- **Honest communication and awareness between institutions and all its members, including and not limited to schools, public transit, and community resources**
- **Increased funding for assistive technology and further assistive programs for those with EDS and providing ways to support them**
- **Supportive childcare for people with EDS**

Awareness and Education for Facilitating Support Groups

Support groups focused on allowing people to feel connected is very important even without the number of gaps in the system as seen with EDS. Further methods to facilitate these support groups can be beneficial for the affected chronic pain and EDS population. These include but are not limited to:

- **Moderators among online or in-person support groups to ensure productive conversations**
- **Increased tools to help assist those that are experiencing loss and to complement other mental health professionals**
- **Connection to resources that are not available for the person**
- **Increased awareness and knowledge of management techniques that are not known by healthcare professionals**
- **Facilitation of dating among those with EDS and other disabilities and the able-bodied population**

Further Research Opportunities for those with EDS

Further research needs to be done to expand the knowledge of EDS and other conditions. Research on many topics is important, however prioritizing them to have the biggest impact on those with EDS are shown:

- **A comprehensive review of the literature involving those with EDS and further gaps**
- **Further research regarding EDS, common comorbidities and its subtypes fueling further diagnosis**
- **Research on projects that are focused on:**
    - **Possible patient advocacy/navigator programs**
    - **Communication guidelines for healthcare professionals to interact with patients and among their interdisciplinary team**
    - **Physical and social accommodations to allow people with EDS to be as independent as they wish**
- **Research regarding EDS and correlations between pregnancy and hormonal influences**
- **Research regarding diets and nutrition for those with EDS and MCAS**
- **Research regarding sleep management and sleep disorders among those with EDS**
- **Research on non-traditional modalities to manage pain among those with chronic pain as well as EDS**

Section 9: Resource Bank

A. Phone Applications

B. Community and Social Services

C. Support Groups

D. Mental Health Resources

E. Sleep Management Resources

F. Pain Management Resources

Phone Applications

Daylio – Mood Tracker

https://play.google.com/store/apps/details?id=net.daylio&hl=en_CA&gl=US

Period Tracker – Period Tracker

https://play.google.com/store/apps/details?id=com.popularapp.periodcalendar&hl=en_CA&gl=US

Step tracker (activity) – Step Tracker

https://play.google.com/store/apps/details?id=steptracker.healthandfitness.walkingtracker.pedometer&hl=en_CA&gl=US

My Pill Box – Medication Tracker

https://play.google.com/store/apps/details?id=eu.smartpatient.mytherapy&hl=en_CA&gl=US

Manage my pain – Pain Tracker

https://play.google.com/store/apps/details?id=com.lcs.mmp.lite&hl=en_CA&gl=US

Super Cook- Recipes by Ingredient

https://play.google.com/store/apps/details?id=com.supercook.app&hl=en_CA&gl=US

ICN Food List- Food descriptions for those with Interstitial Cystitis

https://play.google.com/store/apps/details?id=com.icnetwork.foodlist&hl=en_CA&gl=US

Headspace- Meditation and Sleep

https://play.google.com/store/apps/details?id=com.getsomeheadspace.android&hl=en_CA&gl=US

Community and Social Services

211 Ontario

https://211ontario.ca/

Support Groups

The Mighty – Moderated Support group for those with chronic conditions like EDS and other comorbidities

https://themighty.com/

Mental Health Resources

Ontario Mental Health Resources

https://www.ontario.ca/page/covid-19-support-people#section-4

Free Live Counselling 24/7

https://wellnesstogether.ca/en-CA

Canadian Suicide Prevention Centre

https://www.crisisservicescanada.ca/en/

AbilitiCBT- Internet-based cognitive behavioural therapy program. Program connects you with a professional therapy via online platform, and program offers structured modules that contain activities, videos, and assignments to help address mental health and develop and practice new skills to cope.

https://ontario.abiliticbt.com/home

Bounce Back- Free-skill building program managed by Canadian Mental Health Association. Programs designed for adults and youths and is delivered via an online platform to help address mental health needs.

https://bouncebackontario.ca/

Sleep Management Resources

MySleepWell-Free resources related to techniques to be used to help fall asleep. Includes list of guided audios, YouTube videos, and recommended apps and books, as well as resources to assess your sleep such as a sleep diary, sleep calculator, and sleep hygiene checklist.

https://mysleepwell.ca/cbti/cbti-components/relax/

Pain Management Resources

Take Control Take Charge- Chronic pain self-management free webinar series.

https://takecontroltakecharge.ca/

Chronic Pain Centre of Excellence for Canadian Veterans

https://www.veteranschronicpain.ca/veterans#locations

Appendix

A. Needs Assessment Visual

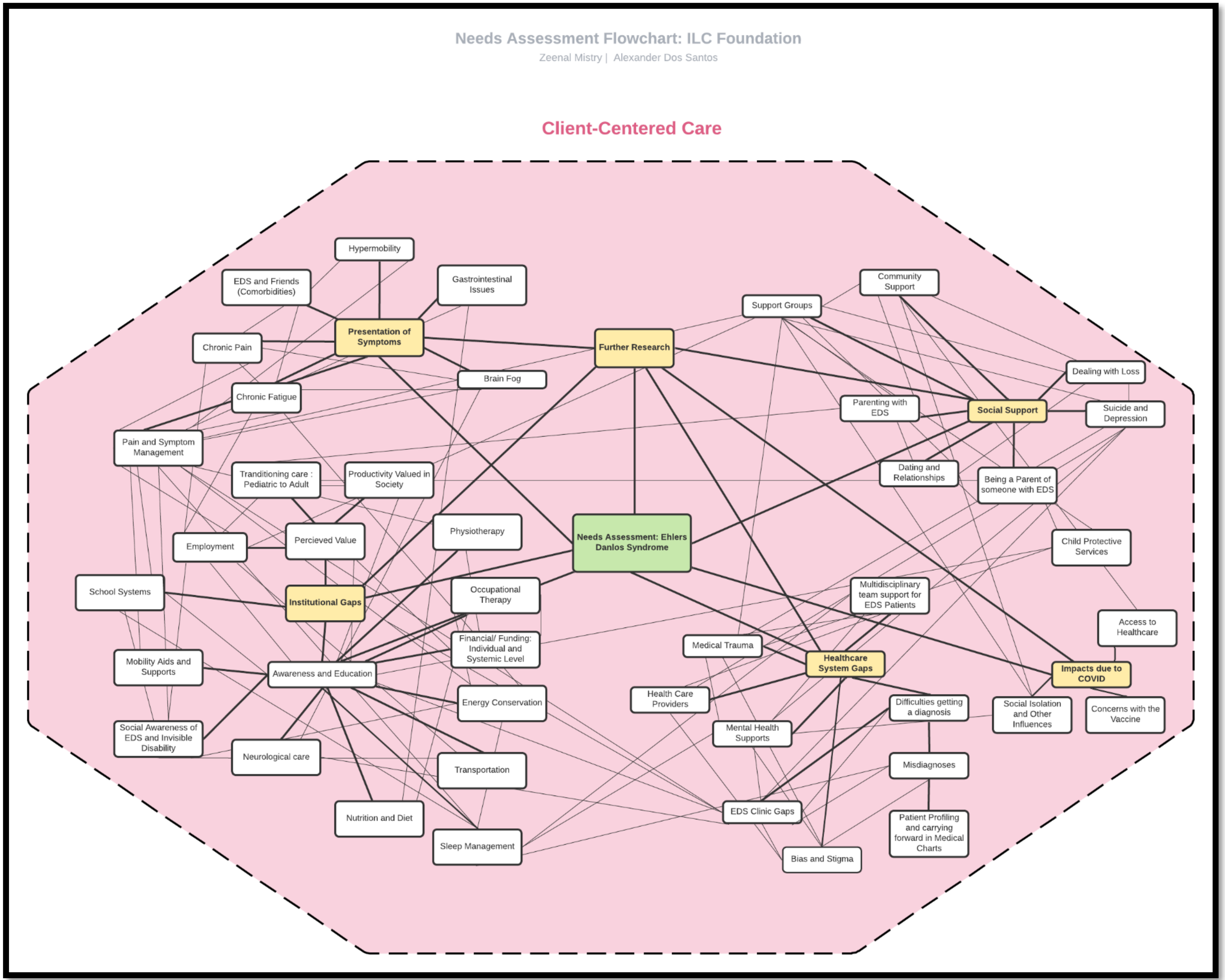

Figure 1: Needs Assessment Visual