Our Stories

Stories and Discussion Questions on the Experiences of Women with Visible and Invisible Disabilities in Scarborough
Land Acknowledgement

The Enable ACCESS Project took place on traditional territory of the Haudenosaunee, the Metis, and most recently, the territory of the Mississaugas of New Credit. This territory is covered by the Dish With One Spoon Wampum Belt Covenant, an agreement between the Haudenosaunee, the Ojibwe and allied nations to peacefully share and care for the lands and resources around the Great Lakes. Today, the land is still home to many Indigenous people from across Turtle Island, and we are grateful to have had the opportunity to work in the community, on this territory.

Acknowledgements

Enable ACCESS is funded by the City of Toronto and is run by Malvern Family Resource Centre.

Malvern Family Resource Centre (MFRC) is a multi-service agency that offers a variety of programs and services to meet the needs of the Malvern community and residents of Scarborough. Women’s Place is a MFRC service that provides programs, counselling, housing support, and service linking to women.

This project would not be possible without the support of:
Thank You

Thank you to the storytellers for sharing your personal experiences of courage and vulnerability. These are powerful stories that extend your ongoing work to advocate for the needs for women with disabilities. In alphabetical order, thank you:

Anette Francis M.
Arundathy Murugesu Marjorie Grant
Debbie Naipaul MS Muminah Muhammad
Jeanette Cox Tracy Bell
Judith Reid Verna Pellew
Lucinda Levair

Using These Stories

These stories were created to build community capacity towards accessibility. They provide a small snapshot into the challenges and needs of women with lived experience with visible and invisible disabilities. Some themes from these stories include having an invisible disability, losing supports when in need, issues in accessing transportation, discrimination, women with disability experience, and the need for more advocacy. Use these stories to start conversations in your community. The end of this book also includes discussion questions developed by the authors to support conversations.

These stories were also created as digital stories. To view the digital stories or for more information, please go to www.mfrc.org/enableaccess.
Our Stories

11 Stories from Women with Visible and Invisible Disabilities. These are true stories which have not altered in any way.

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M.’s Story

*M is an overseas foreign worker and an advocate for caregivers and workers rights. She is a woman with an invisible disability.*
I never knew about mental illness until I was hit hard in life 2 years ago.

As an immigrant, the eldest and the only girl of 3 siblings, a single parent with 5 children, an absentee wife trying to keep a long distance relationship. It speaks volumes on the weight I was carrying.

I have experienced a lot of traumatic events, sexual abuse, losses of loved ones and no chance to grieve from childhood until my professional life and yet, I was able to cope.

When I lost the job that I love without cause at the age of 55. I was devastated. I felt helpless, in fear of being homeless, and anxious. My motivation to live and joy was gone. My job was all I needed to survive.

My illness got worse because my family doctor and psychiatrist does not want to hear me out and address my concerns. But quick in prescribing medication and slow in providing referrals to outpatient mental health programs.

Some community services that I went for support only provided one or two workshops and then I was lost again. There was no continuity or referrals to other services, and the waiting list was too long.

It took me a year and a half to get through the program with the help of new family doctor.

I wish that healthcare professionals, community services and government agencies will collaborate like as one umbrella so they understand and know how to treat people like me suffering from mental illness.
A Tale about Having Few Options by Judith Reid

Judith Reid is a resident of Malvern and is a mental health advocate.

In the community of Malvern, Scarborough, Toronto, a young woman lived alone in a bachelor apartment in a big house. She had chronic mental health disabilities: schizoaffective disorder, panic disorder, social anxiety, and depression.

Her time was spent going to medical appointments. Her psychiatrist in Scarborough, her therapist in Etobicoke, and her general practitioner in Etobicoke. She attended a women’s group once a week at a community organization, and volunteered for the organization a few times a week.
Other than that, she had a lot of time on her hands and no one close by to share it with. She needed more structure to her days, to make the day more meaningful, instead of not doing much all day and potentially getting more sick.

There was a free drop-in program, the only one in Scarborough, provided by the hospital close to her. But the programming was for people with severe mental health illness like schizophrenia. Her needs were different. The young woman needed a place she could socialize with people, make friends, and work on getting better instead of living in isolation. What is lacking in North-East Scarborough is a free daily drop-in program for people with diverse mental health disabilities, not just severe ones.

“Snap out of it!” “It’s a crutch you’re holding onto!” “You just don’t want to work!” “Get up off your @!* and look for a job!” Various family members have said to her.

When she was able, a long time ago, she went to school. She went to work.

It seemed like nobody understood. Not family, no understanding in the workplace, and little understanding in school. It’s illness that you have to deal with on a day-to-day basis. It’s illness you need medication for, therapy, and working at trying to get better.

There needs to be a shift in overall public consciousness about mental health. What mental health disabilities are and how to respond to people with these conditions. It is possible. For example, people know it’s wrong to drink and drive and get that message from various outlets.

She wasn’t a stereotype of mental illness; she was functional. She could think intelligently. She could articulate herself. She laughed at funny things. She loved to dance. She could take care of herself.

As a child, she had a bright future and potential. She had the potential to soar; the sky was the limit. As a child, she wanted to be an astronomer. As an adolescent, she wanted to be a singer, then a visual artist, then an actress, then a writer.

Will the young woman get the community supports she needs and support from family? Or will she collapse flat on her face, debilitated and alone, unable to try anymore? How do you want this story to end?
Introducing Ms. Muminah by Ms. Muminah Sabura Muhammad

MS. Muminah Sabura Muhammad is a happy mother of three who is passionate about making her mark on the world.

As Salaamu Alaikum, Peace be unto you.

My name is Muminah Sabura Muhammad. I prefer to be called MS Muminah.

I have an invisible disability. Nobody will know I have one, unless I tell you. I am me. I am a writer. If you have to give me a label I prefer this one. I wrote this story.

This story leaves me feeling vulnerable and exposed. I think it’s important for me to tell you how I feel here, because sometimes I can’t.
Sometimes I need to tell an important person like: my family doctor; my psychiatrist; or my workers at 3 different organizations, and volunteer coordinator at I.S.S.R.A., something relevant in my life. I don’t know how to find the right words to say what I need to say. My needs lay hidden.

I realized I needed an opportunity to tell my story in the right way.

I have been well for 6 years now because of my own hard work. 6 years.

I need you to know that. I need you, to see me as me.

Me who attended my grandmother’s 100th Birthday. Me who has 2 brothers; 4 sisters a father and a mother. Me who has 3 beautiful children. Me who has, many skills, talents and gifts.

I am a complete whole person

Can you see me now?

My name is Muminah Sabura Muhammad. Please call me MS Muminah
Tracy’s Story

Tracy is a daughter, sister, aunt, cousin and friend to many. She has lived in Malvern since the age of 14. She is looking to give back to her community and others through teaching.

I have a chronic autoimmune disease called systemic lupus erythematosus that can be invisible and visible at times.

Despite having this disease I am just like any other human being. Sometimes people tend to judge me for what I have and not who I am.

Yes, my disease is real. It’s a disease with a 1000 faces. Look past that and you’ll learn that I have desires and dreams, I set goals and carry them out just like anyone else.

Look at me, see me

Turning to a service such as ODSP was a hard decision, the process was intrusive, yet I felt at ease with the intake worker rather than my assigned case worker. I try not to contact my caseworker, they give off this impression that they have control over your life. I don’t like to ask for anything unless I have to, I prefer letting my doctors go through those channels. Interactions seem impersonal.

I’m left feeling uncomfortable, scrutinized and punished for accessing services that are meant to help me. To them I represent a number and not a person, which can easily be dismissed. I am a person that should be treated as one.
Look at me, see me.
Life Happens by Jeanette

Jeanette is a retiree and resident of Scarborough. She is active in the community as a volunteer.

My name is Jeanette. I am an Immigrant from Guyana and came to Canada in 1970. I am a Mother, and a Grandmother. I am retired after working for 31 years. I was a Legal Clerk. I use to belong to a local Union and served on several Committees.

My working life was very busy. Family Life was enjoyable. I entertained friends. Played the guitar, and made frequent trips to Florida.

Life has changed for me in very significant ways. I was diagnosed with Arthritis. My daily life has become a challenge. Some of these challenges are within my control. Others are systemic.

I lived in Oakville in a townhouse with stairs. Having arthritis forced me to relocate. I was part of a community and also part of a church family. Moving meant losing contact with familiarity at a crucial time in my life.
While seeking an alternative accommodations, I discovered many barriers existed for people with disabilities. Architectural designs of older apartment buildings did not comply with today’s standards. Some buildings did not have elevators or ramps. Grab bars are not present in bathrooms. I am very conscious of falling. I live in a low rise private apartment now. Senior buildings have waiting lists that are 3 years long. Housing is a huge issue for disabled seniors. Buildings with too many stairs are unsuitable therefore many people lack adequate housing.

Driving has become increasingly difficult for people with disabilities. Many are forced to use either Wheel-Trans or Public Transportation. Many TTC Buses are not equipped to accommodate people using canes, wheelchairs or walkers. There needs to be more accessible bus routes in the Malvern Area.

Since life happens and anyone can become disabled at any period in their life. I wish that caregivers and government agents would be more sensitive to people with disabilities.
Arundathy’s Story

Arundathy is a resident of Scarborough and has an invisible disability.
I am from Sri Lanka and my name is Arundathy Murugesu. I do have pre-existing disease (Asthma) which is getting worse by some maintenance issues at my apartment.

I have been facing this problem since November last year and nothing had been done to either fix nor address the problems. My health is deteriorating due to these issues and I hope I can get someone to come in and inspect the place.

I am very depressed and stressed due to my health issues and nobody understands. I am suffering from severe anxiety, my heart palpitates very badly, I cannot concentrate on my work very well.

I went to many community centres and asked them for help, they did not help me. I think they don’t believe me and some say I have no problem. English is not my first language and that makes it hard to talk about my problems. Sometimes I am scared and I have faced a lot of problems.

My hope is that someone will give me advice on how to solve my situation and notice the problems I face.

I want a safe life in the future, I don’t know how I can stop this problem. How can I manage?

I want all communities to discuss this issue. My disability is important, I want community services to feel this way too.
Disrespect by Wheel-Trans Taxi and Accessible Van Drivers By Marjorie

Marjorie is a resident of Scarborough and a transportation advocate for women with disabilities.

I have problems with my knees and back so it is very hard for me to stand for long periods. I have a walker with a seat, so in the summer when it is warm I wait outside. When it is cold, snowing, windy or raining I have to stay inside and that’s when I have the most problems.

Before I was disabled I never thought about the disrespectful way disabled clients were treated but now that I am in this position I feel uncomfortable dealing with these drivers.
Most of the drivers are not helpful and very unsociable. When they come to pick me up they knock on the door and walk away immediately so by the time you open the door they have gone back to the vehicle. Usually about 10 minutes before they arrive I sit in my walker in front of the door but it takes time for me to get up and open the door. Now I have to wait about 5 minutes for them to return and they become upset because I did not open the door immediately.

Sometimes they arrive late to pick me up and no apology and sometimes no hello. I went downtown last week and construction was being done on the street so I had to walk down to the corner and wait. It was cold and windy and he was 15 minutes late. No apology, just came out of the van and I got minimal help.

Sometimes they arrive 15 minutes early and they expect you to be ready.

The way I deal with it is not always successful because they start arguing and I am not an argumentative person and I feel badly to call Wheel-Trans and report them so I am glad I’ve got this opportunity.

I believe that lots of clients are experiencing these situations so relating this story will help them and myself deal with similar situations.

Now taxi and accessible van companies can probably give drivers courses so they will be better equipped to deal with us disabled clients. My experience with Wheel-Trans bus drivers is much better. I am feeling really good about this project because I can see lots of good coming out of it. The companies will be aware of what their drivers are capable of and they will be better equipped to deal with our situations. We are disabled people but we need to be treated with respect and dignity and not feel like lesser human beings because we are dependent on them.
Be Happy, Don’t Worry by Verna

Verna is a retired chief, resident of Scarborough, and an advocate for accessible transit.

Educate people more about people with disability, to treat them with respect, do kind things, and remember they are human. We all need love.

I want more accessible units and vehicles in the city.

I used to live in a building with many stairs which made it very difficult to go in and out of the building.

The facilities were not designed for disabled people. The washroom was not equipped with grab bars.

Going shopping and returning with groceries, I needed someone to take it up for me. My neighbours were very kind and they helped me many times.

Presently my home is accessible, which makes living great. When I leave through the garage, the stairs are equipped with a stair lift, and my washroom has grab bars.

The vehicle that I use to take me around is Wheel-Trans. Some of the vans and cars are not comfortable. The drivers pack you in like sardines. Sometimes your legs are hanging which makes it
very uncomfortable when you have knee problems. The Wheel-Trans bus is much better with more studies about how to better transit for people with disabilities so rides can be more enjoyable.

**Anette’s Story**

Anette volunteers with the Enable ACCESS Project. Anette has a unique lived experience as both a woman with an invisible disability and as a service provider.

I volunteer here at Women’s Place. I have a work history in the Social Services Field.

From the time I was a young girl, I have always wanted to help people in need. While in university, I volunteered in a classroom setting with special needs children. I was only there for a few months but I found it very rewarding.
After graduation, I went on to work with children, adults and seniors in different settings as a Service Provider. I enjoyed the interactions. I was very satisfied with my career helping to make other people’s lives better.

I became physically ill while working in the Social Services Field in an area where disability was their specialty – at least on paper. I waited ten years to get that job. My struggle began when my employer just would not support me.

The doctors were of no real assistance to me either, as there was no agreement as to my diagnosis.

I suffered in silence daily.

I tried not to be angry, but I felt abandoned, rejected, betrayed and neglected. The Service Provider now needed to be provided for and no one seemed to be able to do the job.

My perspective has now changed because of my involvement with The Enable ACCESS initiative. I believe that I have been provided an opportunity to contribute and to be heard. I am able to relate to other women’s stories.

My story is a God story and it is still being written.
Debbie’s Story

*Debbie is a resident a Malvern, a proud mother, and vocal advocate for women with disabilities.*
In February 2014, I became ill and disabled. I was now unable to work and could not afford to upkeep my private insurance. Without private insurance, many medical doors closed. I was in need of healthcare, trauma informed healthcare.

Access to trauma based care and clinicians, are already, next to none, in my community. This area simply doesn’t attract them.

I spent many hours, over many days, searching for OHIP covered care that was trauma based.

I was frustrated and stressed. I panicked about my failed attempts. I was worried about the fate of my health.

A local non-profit agency re-opened in my community and expanded its services to include trauma care.

The *Women’s Place* may include hot meals, travelling, emergency services, networking, individual/group counselling, social/exercise groups and more.

It’s a comfort knowing someone understands. But I still face many challenges.

Social assistance issues me $147 for medical travel monthly.

Ministry of Health does not cover allergy medication. Do I buy a monthly TTC pass? Do I pay for the $67 dollar allergy medication that I am very ill without? Do I have an emergency taxi fund, in case? How do I follow medical plans if I cannot afford tests and medications not covered by OHIP?

This debilitates the health and care of mine, and many thousands of Canadian women everyday. We have a very slim chance, of a better quality of life because we simply cannot access our much needed care.

Accessibility. We need a voice. We all need to speak. Accessibility affects everyone. Speak for us. Write a letter or an email to your local politician, attend local community forums, support local agencies like *Women’s Place*. Support doesn’t have to be financial. Give us a voice.
Lucinda’s Story

Lucinda is an active volunteer and advocate for disability and poverty. In her spare time she likes to crochet and be with family.

I was born in 1980 with Craniosynostosis. The symptoms affected my quality of life, no doctor could find out what was wrong with me. The doctors were telling my mom that it was all in my head, that there was nothing wrong with me, I was not fed enough fruits and vegetables as a kid, etc. This went on and on until 1988.

In 1988 I went to CHEO Sick Kids Hospital of Eastern Ontario in Ottawa. They finally figured out what was wrong with me and did surgery within a week. Problem was, I was 8 years old and craniosynostosis is found and treated when you are a baby. The amount of fluid and pressure on my brain was so great it was really bad.
Apparently I have 9 lives, I almost died twice when I was 8 years old

They left me with a 5 inch by 5 inch spot on top of my head where I had no skull, that is why I wore a hockey helmet to protect my brain. I wore the helmet from age 8 to age 16.

Lasting effects I have memory issues, poor balance, spelling and comprehension difficulty, I can’t think math in my head, have extreme head pain, bowel and bladder issues, spinal cord issues, eating issues, social issues and depression. But when you look at me now you can’t see if I have a disability at all.

All throughout school I was told can’t, can’t go to high school, can’t go to college, can’t get a job and live in a group home for the rest of my life. I went to university but did not graduate and lived on my own.

As I was growing up I lived in an all Caucasian, all Roman Catholic, and all Polish / Irish community. There was only a few hundred of us, mostly everybody knew your personal stuff and mostly all of us were related in some way shape or form. I was taught racism and rejection on a regular basis.

The first 48 hours after being home from the hospital, mom and I went to our local grocery store. Nervous about my helmet, an old woman came up to me and told me I was retarded, disgusting and should not belong in the grocery store “you boy”!. I was a tom boy, always in pants and had no hair with a hockey helmet on my head. I did look like a boy.

When I started second grade, I had to relearn everything. Children in my class and school where unkind and bullying constantly. Calling me piggy nose, helmet head, hockey head, peanut head, pee pee brain. You name it, I was called it. Because I looked so much like a boy I would attach stickers, barrettes and headbands to my helmet. I made it work for me, but I never talked to people or had a friend. Many of the kids that bullied me as kid I am friends with on Facebook, and they have kids with disabilities.
Discussion Questions

**M.**

1. How do you think the lack of continuity between services affected M.?
2. M. shared that in her treatment, medication was prioritized over programs. Why do you think medication was prioritized over other options?
3. M. talks about not being heard. How do you think self-advocating affected M.?

**Judith**

1. The woman in this story needed more structure to her day to help her. What could this structure have looked like?
2. The support systems from family, work and school were not there for this young woman. How do you think social context (gender, race, culture, etc.) affect a person’s experience with disability differently?
3. This story was written about a young woman in third person. Why do you think this story was written this way?

**MS Muminah**

1. What does sharing her story make MS Muminah feel vulnerable and exposed?
2. MS Muminah does not share the name of her disability in her story. Instead she says, “I need you to see me as me.” Why do you think she chose to share her story this way?
3. How can we advocate for women who have an invisible disability?

**Tracy**

1. What are some of the things that you have in common with Tracy?
2. What are some of the fears that come up after watching Tracy’s video?
3. What are some of the dreams you have as a service provider? What are some of those dreams, specifically as a service provider serving women with disabilities?
Jeanette

1. What kind of challenges did Jeanette experience in her story?
2. Jeanette talks about systemic barriers. Can you think of any systemic barriers that affect accessibility in the community? Or what makes a barrier systemic?
3. How can caregivers and government agencies become more sensitive to people with disabilities?

Marjorie

1. What are some of the challenges Marjorie’s experiences? How does it affect her?
2. Marjorie talks about the Wheel-Trans driver arguing with her when she advocates for herself. Why do you think Marjorie is met with aggression when she self-advocates?
3. Marjorie talks about courses to train Wheel-Trans taxi and van drivers. What kind of content do you think should be included in these courses?

Verna

1. Why do you think we need more education about disabilities?
2. What can this education look like?
3. How can you apply Verna’s story in your day-to-day life (not just professional life)?

Anette

1. How are the experiences different between a service provider who provides support and a person who asks a service provider for support?
2. Anette says, “I suffered in silence daily. I tried not be angry.” How does Anette’s experience with disability intersect with her gender, race, ability, and other social identities?
3. Anette says, “The service provider now needed to be provided for and no one seemed to be able to do the job.” What could have supported Anette?
**Debbie**

1. Debbie talks about being too sick to work and trying to meet her needs while living on a fixed income. How does her income meet her needs?
2. If Debbie got the supports she needed in February 2014, how would her life be different?
3. Debbie mentions support does not have to be financial. What other support can you give as a service provider or personally?

**Lucinda**

1. How does Lucinda still face the many challenges she experienced when she was younger?
2. How did Lucinda face systemic barriers?
3. How do you think Lucinda built up confidence to talk others and be more open?
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