

Simulation Workshop/Immersive Learning

Disability Education Simulation Workshop Scenario 1: Mali Patel (Booking)

The following role description was developed for use by the actor or volunteer who will play the “Mali Patel” role in the simulation workshop. It’s important that the person(s) playing this role receives this information well in advance of the workshop so that they can prepare. We also advise that you and your team meet with the actor/volunteer in advance of the workshop so they can practice being “in character” (including physical and behavioural affect) and role-playing the scenario. This practice will give you and your team an opportunity to work with the actor/volunteer to refine their role-playing and strategize how to handle various participant interactions that might come up during the workshop in order to achieve the learning objectives.

Role: “Mali Patel”

Scenario: Booking an Appointment with TTY

Background Information

Rationale for the Scenario:

This scenario is inspired by learning needs as described by health care providers in focus groups from the Gateways II Project:

“The time that I did find it hard one time, was someone called, it was on the phone, and someone was speaking on behalf of the hearing impaired person. I just didn’t know what to do in the conversation, cause I kept screwing up. Instead of talking to her directly, I would talk to the other person. And then she’s like, ‘No, you don’t have to talk to me, you can talk to her’. It was hard to get used to the conversation on the phone, because it was like, I kept wanting to say, ‘Can you tell her...’ instead of just directing it towards her. That was a bit of a hard conversation. Because I kept wanting to say it the other way, cause you’re so used to going through the third person. But it was okay to talk to her, because she could talk to you, because she had a special device that she used with the phone. But that took a bit of getting used to. So I was kind of glad when the conversation was over – (laughter)”

Background Information about TTY:

From Wikipedia: A **telecommunications device for the deaf (TDD)** is an electronic device for text communication via a telephone line, used when one or more of the parties has hearing or speech difficulties. Other names include **teletypewriter (TTY)** (TTY is also a term used for teletypes in general), **textphone** (common in Europe and the UK), and **minicom** (United Kingdom).

The typical TTY is a device about the size of a typewriter or laptop computer with a QWERTY keyboard and small screen that uses LEDs or an LCD screen to display typed text electronically. In addition, TTYs commonly have a small spool of paper on which text is also printed — old versions of the device had only a printer and no screen. The text is transmitted live, via a telephone line, to a compatible device, i.e. one that uses a similar communication protocol. In certain countries there are systems in place so that a deaf person can communicate with a hearing person on an ordinary voice phone using a human relay operator. There are also "carry-over" services, enabling people who can hear but cannot speak ("hearing carry-over," a.k.a. "HCO"), or people who cannot hear but are able to speak ("voice carry-over," a.k.a. "VCO") to use the telephone.

Background Details about “Mali Patel”:

Mali is a 45 year old woman who has a medical diagnosis of Spina Bifida, uses a wheelchair, and has acquired hearing loss. She collects ODSP (Ontario Disability Support Program) at \$930.00/month. She got a job straight out of high school in a public library through a neighbour who was a librarian. Mali stopped working at the age of 32 due to anxiety that was later diagnosed as Post-Traumatic Stress Disorder (PTSD).

She also found it very isolating being the only deaf person working in organizations where everyone is “hearing”. Because of this isolation and past experiences she assumes people are not listening to her and not interested in meeting her needs.

Mali lives in supported, subsidized housing where attendant care is provided. She pays \$250.00/month for her one-bedroom apartment and then lives the rest of her life on \$680.00/month. She has no savings. Her hobbies include: online gaming and reading science fiction and fantasy novels. All the games involve building real-life type scenarios within online communities – this is her primary social contact.

Mali experienced extreme bullying as a child and had many traumatic encounters with the health care profession while growing up. This history is at the root of her PTSD.

The following information from an article about lived experience with Spina Bifida (Van Daalen-Smith, 2007) provides insight into the kinds of experiences Mali might have had while growing up:

“Many adults with [Spina Bifida] can remember things such as being paraded naked in front of medical professionals in auditorium-type settings, painful medical procedures being done without explanation, compassion, support systems present or informed consent”

“The grade six class waited for me when I was in grade four. I was invited by one of them into the bathroom and they beat the hell out of me. The principal said: ‘I can’t suspend the entire sixth-grade class, so I’m suspending you.’ That was the last straw. I left the school and went elsewhere.”

“Time and time again [women with Spina Bifida] described instances where they tried to have a say about decisions that affected them; asked for respect and dignity requested assistance with schooling and asked to be included in activities with able-bodied peers. Time and time again their requests were unmet. Their right to have peers, health care professionals, professionals or schools consider their best interests and keep them free from harm...had not been protected. A breach of their right to education and the highest quality of healthcare was evident in their narratives”

The following information from the Gateways I Project focus groups about women’s past experiences with mammograms provides insight into the kinds of experiences Mali might have had while getting screened for cancer:

“The reaction I get [at the hospital] is kind of surprising given that they are healthcare professionals. I come in with a motorized chair and they still ask me if I can jump up on the table. I will of course need some assistance. Then they are so awkward, attempting to get you where you need to be, to be examined, and they don’t follow my directions in terms of how to lift. If I could lift myself, I would do it. I live in a building that provides support, but it’s very difficult to get a staff person available for the length of time due to the waiting period. So I don’t ask for that type of assistance unless I absolutely need it. I’ve gone to all of my doctor’s appointments by myself also due to the privacy issue. But I expect help at the hospitals. It doesn’t have to be about cancer; it can be about anything.”

“Right now I’m my own advocate. If I want a test now, I have to literally go and beg. The politics I’ve had to play to get tests are ridiculous. When you’re disabled, I find you’re put on the lowest part of the list you’re not that important because you don’t contribute to society.”

Set up for Scenario 1

- Small meeting room with several tables and chairs
- 1 table and chair should be placed at the back of the room (away from the entrance) and set up with a laptop for “Mali Patel”, who will communicate with “Suzy, the Bell Relay Operator” through MSM messenger or another instant message service.

- 1 table and chair should be placed closer to the entrance and set up with a laptop for “Suzy, the Bell Relay Operator” to receive messages from “Mali Patel” through MSM messenger or another instant message service. “Suzy” will also need a telephone (no phone line needed) to use as a prop, as she will actually be communicating aloud with the participant playing the role of booking clerk.
- 1 table and chair should be placed near the entrance for the participant playing the role of booking clerk, along with a telephone (no phone line needed) to use as a prop, as the participant will actually be communicating aloud with “Suzy”.

Scenario 1: Booking an Appointment with TTY

Scenario Stem: The clinic is very busy today and you have 100 reminder phone calls to make for future appointments. You are receiving a phone call. Please address the caller's requests. There are only a few appointments open next week – Tuesday at 10:00 and Friday at 3:00.

Presenting Situation: A 45 year old woman with a disability (WWD) who uses a wheelchair with a medical diagnosis of Spina Bifida and acquired hearing loss phones the mammography clinic to book a mammogram. She is using TTY where a live translator in a remote location speaks the words typed by Mali in her home, and then types the words spoken by the receptionist so that Mali can read them on her TTY device.

Bell Relay Operator's Opening Line: “Hi this is Suzy from Bell Relay. I've got a call from Mali Patel. She wants to make an appointment.”

Bell Relay Operator's Behaviour Affect: Flat tone of voice, speaks quickly and is very business-like. She will type everything the participant says verbatim and communicate this to Mali and vice-versa, even if the content of the message is socially awkward.

Mali's Opening Line: *(via Operator)* My doctor referred me to your clinic for a mammogram.

Mali's Behaviour Affect: Anxious and impatient. Mali is very likely to snap. She doesn't want to have a mammogram (see background details above) and doesn't trust people to accommodate her needs. She is especially likely to be rude if the receptionist addresses the translator instead of her.

Empathic Challenges for Participants:

- The Bell Relay operator opens the call and is not very explanatory – her affect is flat as she relays Mali's typed messages.
- There is a substantial delay in communication due to the time it takes for Mali and the Bell Relay operator to type messages.
- Mali is very blunt.

Successful Outcome of Scenario: The actor playing Mali will throw up various roadblocks if she does not feel she will be accommodated appropriately at the clinic. For example, if the staff-member acting as receptionist in this scenario does not ask Mali exactly what she needs and assure her that her disabilities will be accommodated then Mali will hang up without booking her appointment. A successful outcome would look like this: Mali books the appointment and feels confident that she can negotiate disability accommodations. The healthcare provider has asked her what accommodations she needs and collaborated with Mali effectively on how to proceed.

Learning Objectives/Skills/Helpful Feedback for Participants

Learning Objectives:

- Healthcare providers (HCPs) should understand that women with disabilities (WWDs) do work to arrange and attend screening because they often want these tests.
- HCPs should learn that some women have multiple disabilities and that it is essential to ask what kind of accommodations women need to create a welcoming, accessible environment.
- HCPs should develop increased awareness of the life experiences of WWDs (some of whom will have histories of trauma with HCPs) and the importance of communicating clearly and respectfully.

Skills Learned:

- General communication – specifically TTY.
- Communication with WWDs - the importance of addressing the WWD directly, not the translator or Bell Relay Operator

Helpful Feedback:

In addition to other feedback that the SP may provide to participants, if it is appropriate to do so, we recommend mentioning the following Mount Sinai Hospital guidelines about communicating with interpreters:

- Ask the interpreter to speak in first person
- Maintain contact with the patient
- Speak in short sentences
- Clarify and verify
- Mention next steps & ask about any concerns the patient may have