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WHAT'S THE CRAIC? HEALTH CARE FOR DEAF PEOPLE IN NORTHERN IRELAND

Michael A. Schwartz*

ABSTRACT

Northern Ireland, one of the four political entities constituting the United Kingdom ("UK"), is subject to the United Nations Convention on the Rights of Persons with Disabilities ("UNCRPD") because the UK ratified the UNCRPD on June 8, 2009.¹ Article 25 of the UNCRPD requires access to health care for people with disabilities, including those who are deaf or hard of hearing.² A Fulbright scholar at Queen's University Belfast in 2015, I conducted a study of deaf people's access to Northern Ireland's health care system. My study, confirmed over several subsequent visits to Northern Ireland, suggests that work needs to be done to fully effectuate Northern Ireland's compliance with the UNCRPD. Interviews with deaf people, sign language interpreters, and health care personnel underscore three key themes: the need for cultural awareness on the part of health care providers, the shortage of sign language interpreters, and the impact of the interpreter on the dynamic between the deaf patient and the hearing health care provider. The overarching theme of the research demonstrates that there is an urgent need for training for all of the key stakeholders. The article suggests several steps to address these themes.

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¹ The UK also ratified the UNCRPD's Optional Protocol on August 7, 2009, a document that enables an individual to file a complaint with the ratifying country's UNCRPD committee. See *CRPD List of Countries: Convention, Optional Protocol Signatures, Ratifications*, DISABLED WORLD, <https://www.disabled-world.com/disability/discrimination/crpd-milestone.php>. (last visited Feb. 20, 2019).

² For the rest of this article, the term, "deaf," will include sign language users who are hard of hearing or have residual hearing but consider themselves part of the deaf community.

INTRODUCTION

My roots in Northern Ireland go back to my first visit in August 1983, a year after my father had died. He and my mother, both social workers, had visited the Province often during the 1970s, which saw some of the worst violence of the Troubles, the quaint name given to the sectarian conflict between Catholics and Protestants in the northeastern corner of Ireland that killed some 3,600 people—civilians, police officers, British soldiers, and members of the paramilitaries—over a 30-year period starting in 1968.³ I remember being amazed that my parents—mild-mannered white-collar Jewish intellectuals—would not only travel to a war zone but also return home raving about the land of “a terrible beauty.”⁴ Upon my father’s death, I decided to pay a visit to Northern Ireland and have been returning on a regular basis over the last 36 years. Over the course of at least 25 visits, I came to see that access to health care for Northern Ireland’s deaf community is fraught with difficulty for some patients and their health care providers. Therefore, I decided to conduct a series of interviews of deaf people, sign language interpreters, and health care providers in an effort to uncover and illuminate the nuances of communication for deaf patients in the health care setting.⁵

³ See John Dorney, *The Northern Ireland Conflict 1968-1998—An Overview*, IRISH STORY (Feb. 9, 2015), www.theirishstory.com/2015/02/09/the-northern-ireland-conflict-1968-1998-an-overview/#.XGlogC3Mw-M. See also Alan Cowell, *50 Years Later, Troubles Still Cast ‘Huge Shadow’ over Northern Ireland*, N.Y. TIMES (Oct. 4, 2018), <https://www.nytimes.com/2018/10/04/world/europe/northern-ireland-troubles.html>. The paramilitaries ranged from the Provisional Irish Republican Army and the Irish National Liberation Army on the Catholic side to the Ulster Volunteer Force and the Ulster Freedom Fighters on the Protestant side. Rachel Flaherty, *Main Points from Northern Ireland Paramilitary Groups Report*, IRISH TIMES (Oct. 21, 2015), <https://www.irishtimes.com/news/politics/main-points-from-northern-ireland-paramilitary-groups-report-1.2400012>.

⁴ William Butler Yeats, a world-renowned Irish poet, wrote “Easter 1916,” a poem about the failed insurrection against British rule in Ireland. The poem contains one of the most famous lines in world poetry—“a terrible beauty is born”—an expression of Yeats’ emotion about the Easter Monday 1916 Irish uprising that resulted in the execution of a number of Irish rebels. See William Butler Yeats, *Easter, 1916*, POETRY FOUND., <https://www.poetryfoundation.org/poems/43289/easter-1916> (last visited Feb. 20, 2019).

⁵ Qualitative research seeks to understand social phenomena from the perspective of the stakeholders, deriving meaning from their actual experiences. See STEVEN J. TAYLOR ET AL., INTRODUCTION TO QUALITATIVE RESEARCH METHODS: A GUIDEBOOK AND RESOURCE (2016).

UNCRPD ARTICLE 25—HEALTH

The framework for my study is Article 25 of the United Nations Convention on the Rights of Persons with Disabilities, which states in part: “States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.”⁶ Of particular relevance to my study are the following mandates that require State Parties, specifically, the United Kingdom, to:

- Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programs as provided to other persons;⁷
- Require health professionals to provide care of the same quality to persons with disabilities as to others;⁸ and
- Prevent discriminatory denial of health care or health services on the basis of disability.⁹

The interviews with deaf people, sign language interpreters and health care providers highlighted three key themes: the need for cultural awareness, the shortage of interpreters, and a greater understanding of the interpreter’s influence on the communication dynamic. Fleshing out these three themes sheds some light on the extent to which Northern Ireland complies with Article 25 of the UNCRPD.

What follows is a qualitative research study where I drew meaning from the narratives of the key stakeholders in health care: deaf patients, sign language interpreters, and health care providers.¹⁰ Through in-depth interviews of these key players in health care in Northern Ireland, I sought to develop descriptive data from which I

⁶ U.N. GAOR, 76th plen. mtg., U.N. Res. A/RES/61/106, at art. 25 (Dec. 13, 2006), <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>.

⁷ *Id.* at art. 25(a).

⁸ *Id.* at art. 25(d).

⁹ *Id.* at art. 25(f).

¹⁰ This study was the catalyst for a closer in-depth look at access to justice for deaf people in Northern Ireland. Brent C. Elder & Michael A. Schwartz, *Effective Deaf Access to Justice*, 23 J. DEAF STUD. & DEAF EDUC. 331 (2018). Michael A. Schwartz & Brent C. Elder, *Deaf Access to Justice in Northern Ireland: Rethinking ‘Reasonable Adjustment’ in the Disability Discrimination Act*, 33 DISABILITY & SOC’Y 1003 (2018).

could draw inferences based on their experiences. Here are the stories people told me.

METHODOLOGY

In approximately 25 visits to Northern Ireland, I developed a network of deaf and hearing colleagues throughout the Province. This network assisted my efforts in arranging interviews with the participants: deaf and hard of hearing people, sign language interpreters, and health care providers. I attended meetings of various professional groups, social clubs and events to meet local deaf community members who would feel comfortable enough to schedule a time for an interview. While the interviewees were from the six counties of Northern Ireland, many were from Belfast and Derry. All in all, I spoke with over fifty people spread out over the three groups.

I created consent forms in English and worked with a deaf British Sign Language (“BSL”) user to create a YouTube video of a consent form accessible to BSL users. Each interview had two interpreters: an American Sign Language (“ASL”) interpreter and a BSL interpreter, both on hand to facilitate communication. The ASL interpreter converted spoken English into ASL (voice to sign) and ASL into spoken English (sign to voice), while the BSL interpreter did likewise for BSL. Each interview was audio-recorded using digital recording equipment and transcribed by a transcriptionist.

THEME 1: CULTURAL AWARENESS

The term, “deaf culture,” denotes a set of social beliefs, behaviors, literary traditions, history, values, and shared institutions of a community that uses sign language as the main means of communication.¹¹ Many members of the deaf community view deafness not as a disability or illness, but rather as a cultural phenomenon based on sign language. Deaf people identify themselves as part of a community, taking pride in their identity as sign language users in the sense of a community or culture. In short, deaf people regard themselves as a linguistic minority, and many feel misunderstood by those who do not know sign language and are unfamiliar with aspects of deaf culture. Deaf people interviewed for

¹¹ CAROL PADDEN & TOM HUMPHRIES, *INSIDE DEAF CULTURE* (2005).

this project described the general lack of cultural awareness among health care providers as a problem in accessing health care in Northern Ireland.

A. Deaf Interviewees¹²

According to a deaf interviewee, “[health care providers] don’t know [deaf culture], it’s all so superficial and so false, and they think they know, but in reality they don’t. They are scratching the surface, and they need a lot of training.”¹³ The interviewee identified the importance of cultural awareness and empathy for deaf individuals for successful communication between the provider and the deaf patient, and ultimately for the quality of health care provided:

I want [doctors] to understand it’s important that if they communicate with us better, then everything will go better. I can’t expect them all to sign, but they can find a way of communicating with us and they just need to be aware of that. . . . I want awareness. The language skills are never going to be great, I want the awareness [of deaf culture] so that they’re prepared to talk to me.¹⁴

The same interviewee defined cultural awareness as “having an amazing knowledge of deaf culture, deaf issues, deaf mental health, language barriers. . . . So [health care providers] need to understand, have a really good understanding of the barriers, plus the issues caused by those barriers.”¹⁵ Defining cultural awareness as an ability to understand and empathize, he said, “Being aware means that you’ve really got it, you understand how deaf people feel and you understand the best approach for them, the best communication.”¹⁶

This person provided an example of how the lack of awareness on the part of the provider—wearing a mask and sporting a “massive beard”—complicated communication when he was in the hospital:

¹² The citations in this article are to the transcripts of my interviews of deaf people, sign language interpreters, and health care providers. Accordingly, “DS” refers to “deaf subject,” “IS” refers to “interpreter subject,” and “MS” refers to “medical subject.” The page citations are to the interview transcripts, which did not retain the names of the interviewees.

¹³ DS 12, p.11.

¹⁴ *Id.*

¹⁵ *Id.*

¹⁶ *Id.*

The surgeon came and spoke to me with a mask on, so on the way into the [operating room], I said to the surgeon, “I’m deaf and I can’t lip read what you’re saying,” and he kept talking, and I had to actually say to the surgeon, “Would you please lower your mask?” So he took the mask off and underneath he had this massive beard. And that was even worse, and I had to say to him, I mean, I was lying there really ill, really would’ve needed an interpreter but you know, what it’s like when you’re so ill, you don’t have the energy to even try and lip-read.¹⁷

Another interviewee explained the health care professionals’ lack of awareness as follows:

I don’t think they understand that communication itself can actually be something that affects people, and that our culture might be different, our language is different. I just don’t think they get all that. The reality is doctors don’t understand the way that deaf people want to explain things themselves. And if we have a niggle, we’ll just say, “Oh, sure, it’s ok,” because we don’t know, we explain things in a different way.¹⁸

The lack of cultural empathy has consequences for the interaction between the health care provider and the deaf patient.¹⁹ The inability of deaf patients to receive meaningful access to information has the potential to create a discrepancy in the quality of care deaf patients receive as opposed to hearing patients who have fuller access to health care information. Even in appointments for minor complaints or the annual physical, certain behavior by the provider, *e.g.*, the failure to face the patient and make eye contact, hinders effective communication between the health care provider and the deaf patient. One interviewee who relies on lip-reading explained, “When I see a new GP, it’s kind of like, ‘I’m deaf, sorry, can you look at me?’ It’s just deaf awareness really, [it’s] basic communication awareness for

¹⁷ *Id.* at 10.

¹⁸ DS 17, p.14.

¹⁹ Cf. Clifford Geertz, *On the Nature of Anthropological Understanding: Not Extraordinary Empathy but Readily Observable Symbolic Forms Enable the Anthropologist to Grasp the Unarticulated Concepts that Inform the Lives and Cultures of Other Peoples*, 63 AM. SCIENTIST 47 (1975), <https://www.jstor.org/stable/27845269>.

everybody, look at people in the face when you are talking to them, make sure your lip patterns are clear.”²⁰

The lack of cultural awareness extends to the belief about deaf people, for example, that all deaf persons have the ability to communicate by lip-reading and reading written English. These stereotypes can contribute to the difficulty between the deaf patient and the health care provider. One deaf interviewee, who works with the grassroots deaf community, explained the effect of relying on written English and lip-reading to communicate:

[Some deaf people] all struggle with anything that’s written, they do struggle a fair bit. Often, they’ll receive written information and come and see me to see if they can understand it better, so even the smallest thing throws them into a panic. They really panic when anything’s sent to them, and it’s a letter or it’s a report, and I have to reassure them and make sure that they don’t worry about something that’s quite minor. They are much better if they get the information directly in sign language than in a written report.²¹

As we can see from the deaf interviewees in this section, cultural awareness is crucial for health care providers; they need to know about deaf culture, to become aware of their behavior, to rethink their assumptions about deaf people, and to understand the challenge of written English for some deaf patients. In all of my interviews with deaf people, I did not hear a deaf interviewee who told of a health care provider who checked with the deaf patient to see if the patient understood the provider’s written instructions or reports.

Next up are sign language interpreters reflecting on the need for cultural awareness on the part of health care providers.

B. Interpreter Interviewees

Like deaf interviewees, sign language interpreters recognize the importance of health care providers possessing cultural awareness about their deaf patients. For example, this particular interpreter fretted about getting it right in facilitating communication between the patient and the provider:

²⁰ DS 25, pp.13-14.

²¹ *Id.* at 9.

Medical interpreting, you know, is something that really is important to the lives of deaf people. If they got the right medical attention, absolutely that was something important, and why shouldn't they have the same access as hearing people? So yeah, the act of translating medical terms into something that was going to be understandable to my client was a bit like a puzzle to me, and how do I make this complex jargon-filled diagnosis relevant to [the patient]? Equally, how do I get this deaf person's history, how do I make sure that the doctor realizes the importance of what they're [hearing], because it's coming across in a different cultural way?²²

One of the frustrations for sign language interpreters in the health care setting is the health care provider's lack of cultural competence when it comes to communicating effectively with the provider's deaf patient:

I would say when you're looking at the relationship between interpreters, professionals and the deaf people, there's very little relationship. Very often we will be going into appointments and the doctor will think the interpreter is with the deaf person, so we're like an advocate or company for them. They won't really see the deaf person in their own right or give them that independence, which makes it very difficult if you are working with vulnerable deaf people. And a lot of deaf people we would work with in the medical setting are vulnerable in the sense that they won't really have access to the information. Even with an interpreter present, if I just relay the information, they're not maybe going to understand it or they're going to struggle with that level of information. And a doctor very often doesn't care to explain because they just leave explanations as the responsibility of the interpreter, as opposed to treating the deaf person like they would any patient and being thorough.²³

²² IS 1, p.7.

²³ IS 3, pp.2-3.

There is variety in how health care providers worked with the interpreter:

Each doctor surprised me in their approach because everyone was so different, whether it was someone that greeted the deaf person by, you know, making eye contact, bringing them in, making sure they sat down, making sure they were comfortable, and said, “Oh, yeah, the interpreter can sit there, too,” you know, this is all about the deaf person. Then, of course, on the other side of the scale we have doctors who say to the interpreter, “So what’s wrong with your mum now, what’s wrong with your dad?” and you’re just like, “No, I’m the interpreter, I only met [the deaf patient] two minutes ago in the waiting room,” you know? So some doctors were absolutely clueless.²⁴

The above excerpt highlights a problem where the doctor assumes that the deaf patient is the interpreter’s relative and speaks to the interpreter instead of the deaf patient. The doctor not only fails to make eye contact with the deaf patient, a key element in deaf culture and communication;²⁵ he assumes the interpreter is not a professional retained to provide a service to both provider and patient. Reaction to the interpreter varies across the board:

So different, it can vary so much, whether it’s, you know, “If you have to be here, sit in the corner,” you know, “Don’t interfere with my exam,” or, “Oh, my goodness, I couldn’t have done this without you, thank you so much for coming,” you know, “I don’t know how I would’ve communicated, it just would’ve been so difficult,” and it’s like, “Well, that’s why I’m here,” you know?²⁶

One interpreter pointed to the failure of the health care professional to account for the extra time needed to communicate effectively with the deaf patient:

²⁴ IS 1, p.9.

²⁵ Steven Barnett, *Communication with Deaf and Hard-of-Hearing People: A Guide for Medical Education*, 77 ACAD. MED. 694 (2002), https://journals.lww.com/academicmedicine/Fulltext/2002/07000/Communication_with_Deaf_and_Hard_of_hearing.9.asp.

²⁶ IS 1, p.16.

Maybe you'll find [a health care provider] who understands they need to take a bit more time with the deaf person, but rarely would you have somebody who gets it. Usually they see deaf people as lesser or deaf and dumb, you know, that whole dumb thing, especially here in Northern Ireland.²⁷

One big problem outlined by an interpreter was how a health care provider might assume that a deaf patient understood the information coming from the provider. The following passage underlines the importance of being conscious of one's assumptions and taking the extra step to check in with the patient to see if he or she understood the information:

I'll be saying to people, you know, "You need to think about whether that person really got the information." So just because [the health care provider] told them what their condition is, has [the deaf patient] necessarily understood it? What assumptions lie underneath that? And it's hard because they don't know what their assumptions are. There are big assumptions around healthy eating, impact of drugs and alcohol. People assume people have information that they may not have. A very simple tip would be, "Look, why don't you just plan to give a deaf person just a little bit more time, just to check through those things?" It takes longer because the doctor needs to check what their assumptions are. So, you know, the doctor needs to understand, [the patient] needs more time.²⁸

Some doctors did not understand that some medical terms needed elaboration in sign language in order for the patient to understand the meaning of these terms, nor did they know about the

²⁷ IS 3, p.5.

²⁸ IS 4, p.15. Incidental learning is accidental, indirect or unplanned learning. *See, e.g.,* VICTORIA J. MARSICK & KAREN WATKINS, *INFORMAL AND INCIDENTAL LEARNING IN THE WORKPLACE* (2015). People with typical hearing have access to general information through, for example, conversations with others who can hear and speak, radio and television programming, academic lectures, and commercial advertisements. Deaf people, by the nature of being deaf, miss out because their access to oral and aural communications is limited without appropriate auxiliary aids and services like sign language interpreters and captioning.

cultural tendency of some deaf patients to “ramble” when asked for their history during a medical examination.²⁹

But I’ve also had a doctor become quite angry at the deaf patient because of the cultural misunderstandings. The doctor seemed to have quite a short fuse anyway, but the patient liked to tell the story, liked to give the whole background to their problem, which, you know, is fine. So I was relaying that, trying to get the information across, and the doctor had absolutely no time for it and couldn’t understand why, if he used a medical term, the person couldn’t instantly reply whether that was in their family history or not. The doctor did not understand that the term might be well known in English but not have [a corresponding] sign, so I need to explain it, and even then the [patient] might not quite get it.³⁰

An interpreter pointed out that deaf people are challenged in the area of “incidental learning” where because they miss key communications, whether in conversation or on TV or the radio, there are gaps in their knowledge, gaps that the interpreter has to deal with:

[In an] appointment you’re maybe filling in a lot of gaps that deaf people just don’t pick up on naturally from TV or radio or from family discussions, there’s maybe certain things they just don’t know about. So you just need time to fill that out. So just a bit of extra time, and patience as well on the part of the professional, and also open-mindedness and an understanding that deaf people are like anybody else. I think a big thing is more awareness on the part of the medical professional. Awareness really is massive.³¹

²⁹ By “ramble,” I mean to describe a cultural tendency in the deaf community where a deaf patient will tell their medical history in a style of discourse where the details are embedded in a story with many seemingly unrelated strands that amount to, in the deaf patient’s mind, a cohesive and coherent narrative. The health care provider, on the other hand, may misunderstand this phenomenon as evidenced in the interpreter’s recollection. Barnett, *supra* note 25.

³⁰ IS 1, p.10.

³¹ IS 3, p.7; Peter C. Hauser et al., *Deaf Epistemology: Deafhood and Deafness*, 154 AM. ANNALS DEAF 486 (2010).

Another interpreter reinforced the message that the health care provider needs to do the work of ensuring that the deaf patient understands the information the provider is giving the patient:

So [the health care providers] need to understand that they need to use the interpreter's skills, but they also need to make sure that the information's clear, that the jargon is restricted, and the point that they give is clear to the deaf person, and allowing that deaf person the opportunity to respond, not to rush it. Because some deaf people, for whatever reason, don't take on the information very quickly, you have to feed it to them in little bits.³²

Sometimes an interpreter needs to educate the health care provider about what access is effective:

When things go wrong, I become a cultural mediator. A deaf patient was going for an x-ray, and I was to stand in the room beside [the x-ray] because they didn't want to, you know, expose me to the x-rays. They'll just give the deaf person instructions. I was thinking, "Well, how are you going to give [him] instructions?" You know, "Oh, yes, we need [the patient] to hold his breath for fifteen seconds, then we need him to release, then we need to do . . . ," and really detailed stuff. I was thinking, "Maybe you just want to give me a lead-lined vest to put on because I am here to interpret, I do need to be in the room where he can see me."³³

An interpreter's feedback can help the health care provider perform better when dealing with a deaf patient:

Or if a deaf person has been medicated, and [the health care provider] says, "Oh, just tell them this," and I'm thinking, "Well, you don't need muscles to be able to hear, but you need muscles to be able to focus your eyes to see me, you know, you've given this deaf person medication, communication is over." I always make the doctor or nurses aware of that and say, "You know, once you press that button or once you inject, there will

³² IS 7, p.7.

³³ IS 1, p.10.

be no communication for the next two hours.” So that’s an issue.³⁴

Asking the deaf patient for their preferred communication mode is important. An interpreter narrated how a health care provider, in this case, a social worker, thought that the deaf patient did not need an interpreter because the communication went well:

Last week a social worker was going out to the house to review services for my [deaf] parents and she phoned me before she went and she phoned me after, and I’d briefed her because I couldn’t be there. I had an interpreter for the meeting. She phoned me after the meeting, and she said, “Next time I won’t need an interpreter, your dad and I understand each other very well.” I said, “Do you really? That’s interesting because my experience is, dad’s not a great lip-reader. He speaks well, but I don’t think he’ll have understood you.” So I checked with the interpreter, “Did my dad watch you or the social worker?” and she said, “Dad watched me the whole way through.” I also checked with my dad, and my dad said, “Oh, no, I need an interpreter.” So it’s this lack of understanding that speech equates understanding, and that’s a big thing.³⁵

Another interpreter cited the importance of eye contact between the health care provider and the deaf patient:

You do have the doctor who sits and faces the computer, and you know how important eye contact is to deaf people. So they’re sitting facing the computer and they just won’t turn round, which is very awkward.³⁶

Interpreters also spoke to the tendency of the health care provider to speak to the interpreter instead of the deaf patient, describing how a typical conversation went down:

“No, I’m actually here as an interpreter, this is not my mother, and would you like to address the questions to

³⁴ *Id.* at 14.

³⁵ IS 4, p.10.

³⁶ IS 3, p.9.

your patient? I will happily interpret,” and the doctor just remained a bit clueless, saying, “Oh, well (mumbling noise), what’s wrong with her anyway?” So you just can’t get through to some people.³⁷

In sum, sign language interpreters echo deaf people in urging health care providers to possess some cultural awareness about deafness and deaf people. This awareness facilitates the work of interpreters as they bridge provider and patient; understanding the need for time to explain medical terms and concepts is important and helps ensure a higher quality of care. If the provider is aware of the problem of “incidental learning,” where deaf people may have gaps in their knowledge, he or she can be more receptive to the interpreter’s feedback. Interpreters are a source of education for the provider, assuming the provider is open to the feedback.

Next up are health care providers reflecting on the need for cultural awareness on their part when treating or caring for deaf patients.

C. Health Care Provider Interviewees

Health care providers ranged from being clueless about deaf culture to being “deaf aware,” cognizant of deaf people’s linguistic identity and sensitive to the parties’ need for a sign language interpreter to facilitate effective communication between provider and patient. At one end of the spectrum were some providers who regarded deaf people as invisible. A practitioner who sees patients and lectures at a local medical school acknowledged that “the statistics say that we have a lot of patients who have at least some degree of hearing loss, and I’m sure a lot of the time we don’t actually see that but we miss that, you know?”³⁸ This practitioner has an induction loop in his office, but admitted he did not know its location.

Some health care providers perceive deaf people as strictly defined by their deafness:

I think the big problem as well is, you know, the hearing professionals just see the person as deaf, they can’t hear, and [the provider] has no concept of, you know, the different levels of language and the fluency

³⁷ IS 1, p.10.

³⁸ MS 7, p.5.

and, you know, or “disfluency,” and it depends on education and so many things, and they just, they don’t see any of that at all. They just see that they’re deaf, they don’t hear.³⁹

A second-year medical student explained how he saw the role of the sign language interpreter in the health care setting:

I think it’s to make what I say accessible to you and to make what you’re saying, or trying to communicate, accessible to me, because otherwise things are going to be missed between us. As much as we try, we are going to miss out parts of the conversation, whereas if the interpreter’s here, you’re going to hear what I’m saying, and I’m going to hear exactly what you’re saying. So that’s my understanding of it anyway.⁴⁰

Queen’s University Belfast offers a course for medical students enabling the students to meet deaf people, and exposing them to deaf culture and sign language. Deaf speakers conducted scenarios enabling the medical students to interact with and “examine” deaf patients to get a taste of what it would be like to communicate with a deaf patient without a sign language interpreter.⁴¹ The scenarios involved interaction with a deaf patient who could not lip-read and write English notes. As one participant recalled, “These poor medical students had to really try and gesture and act it all out, and that was totally not normal for them, they weren’t used to this at all. So, they had to try and adapt to this. There were tears, some of them started crying.”⁴² The student felt that it was “good that that happened, so now at least if they have a deaf patient in practice, well they’ve communicated with a deaf person before, so it has happened before and they’re not as, not as scary as it was, and they know.”⁴³

A deeper insight into what life is like for a deaf person impressed another medical student taking the course at Queen’s University:

Well, I think apart from like learning a new language the thing that really struck me most was how little I had

³⁹ MS 12, p.24.

⁴⁰ MS 10, p.16.

⁴¹ MS 9, p.11.

⁴² *Id.*

⁴³ *Id.*

actually thought about communicating with a deaf person. I mean I think maybe because I'm hearing, I always think more about maybe the person's family and the other people, you know, how they would deal with the difficulty, as opposed to actually thinking about how the deaf person would deal with the difficulties that they may have. And I think for me that has really impressed me the most in the course, that, you know, getting to think about how a deaf person would live from day-to-day as opposed to just thinking, that person's deaf, they can't hear, you know, obviously it's problematic, but not really thinking about how, you know, day-to-day it would affect their lives.⁴⁴

Another medical student who took the course at Queen's University recognized the need to take time in communicating with a deaf patient:

Well, what struck me the most is surprisingly, I think, a lot of people, when they're not exposed ever to deaf people, they can't, they just don't try to communicate. What I've heard a lot is that the deaf person will maybe say, "What?" or they just need a little more time to understand, but that's it, they're off and that's the end of it. Or maybe [the provider] is a bit like, what's the word, like condescending, you know, because, just because they can't hear, it doesn't mean [the patients] don't understand. You just need to take a little more time to help.⁴⁵

The same student went on to say:

It's just important to be aware, yeah, just to be more aware. I just don't think many [providers] are aware of it, and, yeah, it's just strange that it's not more popular, that we have to learn sign language, I think. Because although it's a minority of people, [deaf people] are still part of the UK, aren't they? They're still British citizens, you know.⁴⁶

⁴⁴ MS 10, pp.2-3.

⁴⁵ MS 6, pp.4-5.

⁴⁶ *Id.* at 5.

A fourth-year medical student, also a graduate of the deaf awareness course at Queen's University, pointed out the importance of taking the time to actively listen and question his deaf patients in a dialogue accessible to them:

I'd be trying to target the language at a level that they could understand fully, but I think with any patient you're trying to target the language at a level they can understand fully. Obviously if a really well-educated person comes in, I wouldn't be talking to them the way I would talk to somebody who doesn't maybe have such a good grasp or understanding. So just try and target the language in a way that I would with anybody, but I would just try and sign visually, and I would ask them lots of questions. I think I'd ask them more questions than a normal consultation with someone who's hearing. Not more questions about what's wrong with them, but when I was explaining something, I would ask [the deaf patient] more questions to make sure they were understanding, and I'd definitely make sure I asked them to feed back to me what I had explained, definitely.⁴⁷

This student understood that taking this kind of care for a deaf patient "would be quite hard to keep the consultation within ten minutes, I think they need a double appointment."⁴⁸ The student went on to point out that "it's a cultural thing, deaf people, some deaf people, some older deaf people from Northern Ireland might like to break into a very long story about whatever their illness is, so that's definitely an issue too. Not the younger ones, the older community."⁴⁹

A social worker declared that the official recognition of BSL helped the deaf community by raising people's awareness:

Things are improving. When sign language was recognized as an official language, that has helped enormously. It has professionalized the need and the services and the recognition that sign language is an actual language. It's more awareness, it's on the

⁴⁷ MS 9, pp.6-7.

⁴⁸ *Id.* at 7.

⁴⁹ *Id.*

television and children et cetera can maybe learn it at school, so I do think that has helped.⁵⁰

One discovery, though not surprising, stood out during my study: younger medical students who had the benefit of the Queen's University's course on deaf culture enjoyed greater awareness than older practitioners who had had no exposure to deaf people or deaf culture.

A culturally aware doctor went on to emphasize the importance of including deaf culture and the challenges facing deaf people in society in medical education:

I think that medical students should have a session where they're given an insight into what life is like for a deaf patient and what life is like in the deaf community, because most doctors qualify [for licensure] without really having been taught anything about life as a deaf person, and about the communication challenges and all the implications that there are in being deaf. They're quite unaware. Therefore, when they have a deaf patient to deal with, it's awkward, and part of what we do unintentionally is try to get the consultation over as quickly as possible, you know, bring it to an end because it's difficult, because we're uncomfortable communicating. Therefore, I think it would be good for [medical students] to have some time to be given an insight into what life is like for a deaf patient.⁵¹

Asked if deaf awareness made a difference in the provision of health care, a fourth-year medical student fluent in BSL responded:

Yeah, hopefully, I think so. I've seen a few deaf patients as a medical student, and I think I know how to work with interpreters, and I know how important it is to have an interpreter and things like that, which other doctors might not be a hundred per cent as aware of. I've got some of the cultural things of deaf people just from having deaf friends. So, I think it does give me an insight that other doctors might not have and that's very

⁵⁰ MS 13, p.20.

⁵¹ MS 11, p.3.

hard to learn. You have to see it and be in it to get a grasp of it, you can't just be taught it.⁵²

Although this particular doctor had rarely worked with an interpreter, he was sensitive to the implications of ineffective communication on deaf patients' health care:

[Working with an interpreter] is quite rare, it's very infrequent. I mean, it's a little bit like patients with learning disabilities who don't fight for their rights or don't push to get best care. They end up being overlooked and they often don't get as good medical care as patients who are well educated, and I think the same may well be true for deaf patients, that because they experience being somewhat ostracized or isolated, they don't go and press and demand the medical care that other hearing patients do, and so by default they get poorer care. I suspect, and if we did research to look at the general health and well being of the deaf population, it may well be significantly worse than the health and well being of the equivalent hearing population.⁵³

As the preceding section about cultural awareness for health care providers makes clear, experience and exposure to deaf people, deaf culture and sign language helps inform a health care provider about treating deaf patients. We now turn to the second theme that emerged in the interviews: access to interpreters.

THEME 2: ACCESS TO INTERPRETERS

A. Deaf Interviewees

For many deaf people, sign language interpretation is necessary in health care situations to ensure that the deaf patient successfully communicates his or her problems to the doctor for accurate diagnosis; and for the doctor to communicate questions to produce a diagnosis, prognosis, and medical instructions for treatment. If an interpreter is not present to facilitate communication, there is an increased risk of miscommunication between the doctor and the patient, which can lead to dangerous and even life-threatening consequences.

⁵² MS 9, p.2.

⁵³ MS 11, p.4.

A common theme amongst deaf interviewees is the shortage of qualified interpreters for medical appointments. Even when an interpreter is available, he or she may not always have the appropriate level of training and experience to interpret in the medical setting because this setting requires knowledge of specialized vocabulary and experience with processes common to the practice of medicine. As one deaf interviewee explained, “Here in Northern Ireland, we have very few, really competent interpreters. That’s the reality. There are more interpreters, but the quality isn’t great. We need quality and we need high standards.”⁵⁴

Interpreters who are not experienced with the medical setting, or who have undeveloped skills can make the communication between the health care provider and the deaf patient challenging. One deaf interviewee described the work he had to engage in when dealing with a difficult-to-understand interpreter:

I’m always saying, you know, it’s great, thank God I’ve got an interpreter. It’s better to have anybody than nobody. But sometimes I just have to make do with someone who’s okay but probably not my first choice. Sometimes I get people that I’m not that comfortable with, and then they don’t really [understand] me when I’m saying things, and then I have to repeat myself regularly, and it can be difficult. Now that doesn’t happen very often, it’s rare, but it can happen. If that happens, I’ll know not to book that person again, you know, I do believe in giving people a chance; people have to develop their own experience and knowledge. So, I do bring people in and give them a chance.⁵⁵

A deaf interviewee explained that without an interpreter, You’re left writing notes because there weren’t any available. I felt that the doctor would just write enough to keep me quiet. I could tell from his body language that he didn’t want to spend any more time. One time, I was in [the emergency room], and the doctor just wrote a few things down. I was kind of disappointed

⁵⁴ DS 17, pp.9-10.

⁵⁵ DS 4, p.8.

because I knew he had more to say, but because he was writing it down, he wasn't saying much.⁵⁶

The patient knew that notes consumed the doctor's precious time.

Asked what medical appointments were like without an interpreter, a deaf interviewee replied:

Awful, because I would write a bit down, they would write a bit down, I would write a bit down, and sometimes the doctor would write a whole big scrawl. I couldn't read their writing, and I'd have to get them to write it out in block capitals to try and understand what they were writing. They would come out with these big words that I just don't understand at all, and you end up just pretending to understand because, well, all I would do is take the piece of paper away that all the notes were written on when I left the doctor's, and then ask [someone else] what the words meant. Having an interpreter means I get the full [picture] because I'm not missing out and having to write things down. I don't want to miss any of [it]. It's really important to have an interpreter.⁵⁷

A deaf interviewee described the importance of the interpreter's role in facilitating clear communications between him and his doctor:

With the condition I have, I have to clarify a lot of the time what medication I'm meant to be taking. I would be very confused if that wasn't interpreted because very often there's a list of medications that I need to follow, which is quite easy to get confused about. So, if the interpreter is there, very often the interpreter will sit beside the doctor, and I have to make sure that the interpreter's aware I need them to interpret everything.⁵⁸

The process for securing the service of an interpreter in the medical setting varies. Sometimes the deaf patient may ask the health

⁵⁶ *Id.* at 11-12.

⁵⁷ DS 6, p.12.

⁵⁸ DS 8, p.7.

care provider to secure the interpreter, and sometimes the patient may book the interpreter. A deaf interviewee noted, “It’s an individual decision. Some deaf people know they can ask the hospital, and some deaf people don’t know that they can, and they would go there and there might not be an interpreter. It depends.”⁵⁹ The interviewee went on to describe her method of securing her preferred interpreter:

I can make the phone calls, I can ask [the interpreter] if they’re available. If it’s a female issue, I know I prefer a female interpreter, right? But if it’s general, and we are sitting there and talking with the doctor, then I don’t mind, I don’t care who the interpreter is. So I would go through my preferred list of interpreters, I would pick who I want, I’d let the hospital know that they need an interpreter. I would let them know that they are responsible to pay for it.⁶⁰

Advance planning and scheduling improve the odds of receiving an interpreter for a medical appointment. A deaf interviewee discussed scenarios where he will proceed with an appointment without an interpreter:

Very much depends on whether I would get an interpreter that day. It just depends on whether there’s any availability. It’s difficult getting an interpreter to come in last minute, so you can be a bit stuck there. If I’m in the hospital and I’m ill, I’ll stay. But say they need me to go for a scan for instance and there’s no interpreter available, nobody’s free, if it’s really important that I need the scan, I’ll go for the scan, but if it’s okay to wait until the interpreter is free, I’ll go for that scan when the interpreter’s there.⁶¹

Medical emergencies are by nature unscheduled and present a challenge in obtaining an interpreter. An emergency room patient described hospitalization leading to a medical procedure where an interpreter was not provided. His story illuminates the potential life-threatening consequences that could have resulted from the lack of an interpreter:

⁵⁹ DS 7, p.12.

⁶⁰ *Id.*

⁶¹ DS 8, p.5.

When I was about eighteen, I had meningitis. I was rushed to hospital. My family was away on holiday at the time, and I was on my own. Nobody knew what the problem was. I was vomiting, I was bringing up blood, very intense headaches, didn't know what the problem was. [Doctors] ran some tests, they took fluid out of my spine. I didn't know what was happening. They just put this thing in my spine and took fluid out. The nurse said, "Go here, go there," and all I knew was what I was being told. This needle went up into my spine, and I didn't know what it was for. I read the medical information about meningitis and realized afterwards that you must stay absolutely still [during the procedure]. Well, at that time I didn't know [that] because people were just talking at me and I didn't know what they were saying. I couldn't move because I was in so much pain, I found it very, very sore, but I did not know that I wasn't supposed to [move]. I was just very lucky.⁶²

So, as the preceding section with deaf interviewees asked about interpreters shows, there is unfortunately a shortage of interpreters in Northern Ireland that impacts on whether deaf patients receive effective communication access in the health care setting. A corollary of the problem of supply is quality: interpreters need more and better training in order to adequately and competently handle encounters between deaf patients and their health care providers. As some deaf interviewees pointed out, written notes are no substitute for sign language interpreters.

Next up are sign language interpreters reflecting on their limited numbers and outlining some of the challenges they face in the health care setting.

B. Interpreter Interviewees

The history of oppression that is common to many, if not most, deaf people, cautions one interpreter, must be taken into account when interpreting for a deaf patient in the health care setting:

⁶² DS 17, p.4.

I know that we have to be very careful as interpreters not to overstep our boundaries too much and we've not to take their power away at all. It is very much about the deaf person having the power, it's their health, they need to know what it is that is wrong with them, but at the same time they've grown up with an overprotective mother or family member who has never let them have that power. I'm not asking the question, I try to ask the question in such a way that I'm finding out what they would want to know or what they would need to know.⁶³

As noted earlier, limited access to interpreters is a commonly recognized problem. From the interpreters' perspective, the limited access results from a supply crisis, which in part stems from a lack of proper training in medical situations. There is also another factor—the reluctance of health care providers to call for a sign language interpreter when a deaf patient shows up in the office, as recounted by an interpreter:

Well, it's still a big problem here because a lot of doctors and hospitals won't book interpreters. We've known of some deaf people that have been lying in hospital for over one week, really ill, and have had no interpreters because the hospital hasn't bothered phoning to get an interpreter because of the cost. I think the problem is, the managers are saying, "You have to look at the cost for your budget, for your department." Also, a lot of the professionals think "Deaf person, that's fine, we can write."⁶⁴

An interpreter recalls that some deaf patients are reluctant to ask for an interpreter.

Our view is the Deaf community has a lot of power, you know, because at the end of the day, the law here says it's their right to have an interpreter under the [Disability Discrimination Act]. So, if they wanted, they could text the agency and say, "Look, I'm in

⁶³ IS 6, pt. 1, p.14. For a close-up look at the history of deaf oppression, see PADDY LADD, UNDERSTANDING DEAF CULTURE: IN SEARCH OF DEAFHOOD (2003).

⁶⁴ IS 7, p.7.

hospital and I need an interpreter.” The agency would go, “Fine, we’ll get you an interpreter.” The Trust can’t say, “Oh no no no no,” because they’re discriminating against that person’s right. So [deaf patients] have a lot of power, but they don’t realize it.⁶⁵

An interpreter mentioned a phenomenon I call “white coat anxiety” that stems from the deaf patient’s perception of the doctor as being “too busy” to bother with effective communication access:⁶⁶

I was just going to say, you know, there’s always a perception that doctors are such intelligent, academic, learned people, and sometimes the deaf person doesn’t like to feel they’re wasting the time of this learned person. So, they’ll walk in, ask their burning question, and if they don’t get the full answer, they don’t always pursue it because they feel like maybe they’re being silly, or that the doctor might think that they’re being silly, and I don’t mean silly, I mean as in they’re displaying their lack of knowledge, you know. I feel like it’s a two-way street; the doctor has to say, “But that’s why I’m here” or “I’m here for you to ask these questions.” But the doctor doesn’t always pick up on that, and I find it very frustrating a lot of times to walk out [and] the deaf person will quite often say to me, “What was that all about? What do you think [he meant]?”⁶⁷

An interpreter recounted feeling the need to educate deaf people about their right to communication access, in short, to be self-advocates:

We have to explain to them, “Look, you have to be comfortable with your interpreter. If you don’t like someone or you don’t understand them, you don’t have

⁶⁵ *Id.*

⁶⁶ Marjorie DeVault et al., *Mediated Communication in Context: Narrative Approaches to Understanding Encounters Between Health Care Providers and Deaf People*, 31 *DISABILITY STUD. Q.* _ (2011), <http://dsq-sds.org/article/view/1715>.

⁶⁷ *IS* 6, pt. 1, pp.10-11.

to stay with the same person, you have the choice. It's up to you who you prefer."⁶⁸

A doctor insisted on having a family member sign for the deaf patient:

So in January my dad had a bit of a heart attack as well as pneumonia and the cardiologist came to the bed, and I was standing there. I said, "I'm not allowed to interpret this consultation," and the cardiologist said, "Well, you're going to because I need an interpreter," and we went ahead and had the consultation. Now to be honest, I knew I interpret for my dad perfectly well. It wasn't that I wasn't going to do a good job, and I didn't mind doing it, but I needed to put my boundaries up. But the cardiologist (clicks fingers), like that, was in with "Well you're interpreting, you're here, you're doing it."⁶⁹

This family member in the above quote happened to be a trained professional interpreter who wanted to function as a daughter, not an interpreter. While every interpreter knows how to sign, not every signer knows how to interpret. What about family members who know how to sign but not how to interpret? Do health care providers know the difference so as to protect the integrity of the communication between provider and patient?

Another interpreter recounted a story that illustrated the danger of a family member serving as an "interpreter" for a deaf patient:

A social worker told me at [the hospital], "We're having real problems with this guy refusing medication. He's been admitted in intensive care eight times, refusing all medication. We need to get to the bottom of this." So I went in, and in the course of the interaction the doctor provided some information for this guy about his condition and basically told him how serious it was. The guy said, and I can remember this, the guy signed back, "Oh, do you mean if I take my tablets, that won't happen?," and the doctor said, "That's exactly what I'm telling you." The guy said, "Oh, I didn't know that." It

⁶⁸ IS 7, p.7.

⁶⁹ IS 4, p.16.

turned out that the guy had been going with his family to the doctor's for years, and [while] his family was lovely, they were a very warm, caring family, they meant the best for him. But he wasn't getting information. Nobody challenged the fact that his family was coming in to interpret for him. So the message about the medical profession needing to take responsibility for [communication access] and not leaving it to family is one that's still not getting out there, people still don't understand.⁷⁰

Part of the problem in securing an interpreter may have something to do with the fact interpreters learn a great deal about deaf people in the course of their work, and the potential for crossing boundaries makes some deaf people uncomfortable. As one interpreter recalls:

Because for some people, it's like, as interpreters we have a lot of information about people, which isn't nice, you know, we hold a lot of information because of the nature of our work. So if I'm working with a particular person I will do maybe a lot of the medical, but I won't go and do any of their finance. Maybe they want to go to [an agency], talk about issues with benefits or whatever, I will say, "No, no, choose another interpreter for that because I don't want to know all your business."⁷¹

The boundary issue between the interpreter and the client further reduces the pool of interpreters available for medical consults. As one interpreter recalls, she will

arrive independently. Sometimes I will never have met them before which, you know, suits a lot of deaf people because often they'll have their own regular interpreters for every other aspect of their life, but in medical settings you don't really want the person that's going to be making small talk in the office kitchen to be interpreting your intimate exams.⁷²

⁷⁰ *Id.* at 15.

⁷¹ IS 7, p.7.

⁷² IS 1, p.11.

Setting a boundary is important for members of the deaf community, and this interpreter interviewee is sensitive to some people's hesitation to use the same interpreter for medical consults as for other purposes. He acknowledges that deaf people prefer to rotate interpreters so that no one interpreter knows everything about a deaf person's life: "It means one person doesn't know everything, and it means [the deaf person does not] have to feel awkward if you meet the person [in another setting] because you know everything."⁷³

A family member of a deaf patient describes how the paucity of interpreters required her to spend time at the hospital seeking an available interpreter so that she could do errands in support of the deaf patient:

[At the hospital], we spent all day, I was texting to get an interpreter, there were no interpreters free. I couldn't just walk away and leave my mum sitting in [the emergency room] and going through admission and everything. When the interpreter came, I was able to run around and get things, sort stuff out, bring her clothes, but then the interpreter had to go, so I had to stay. I'm texting for interpreters, there are no interpreters free at the last minute because there's not enough interpreters. So I had another fourteen-hour day at the hospital. They should've been bringing interpreters in and they still weren't doing that, and it was difficult.⁷⁴

The paucity of training programs for sign language interpreters poses a significant problem in terms of developing a pool of interpreters skilled enough to facilitate communication between the health care provider and the deaf patient:

Interpreters do need to get trained in medical stuff, and it's not happening. So, for example, here all the sign language teaching in Northern Ireland is being done in such a way that students come right through all their language teaching never having had medical vocabulary. Then they go through interpreter training, and they [still] don't have medical vocabulary. Sign

⁷³ IS 7, p.8.

⁷⁴ IS 4, p.9.

language teachers are not teaching that at the minute, so what I would suggest is that [medical vocabulary] goes into sign language teaching, and that there's a whole need for a whole raft of medical interpreter training here in Northern Ireland, which is not happening at the moment.⁷⁵

The lack of medical interpreting training had real world consequences for a beginning interpreter:

I was being put into any type of medical setting, whether it be a hospital or a doctor or anything. And I found that to be very challenging because I didn't know the people, I didn't always know [deaf patients'] different ways of signing depending on what school they'd gone to, and I was travelling to areas I didn't know. That was very confusing, and I was doing that without having had any training at that point because I was put into interpreting situations straight off, nobody was monitoring me, there was nobody checking me, I didn't have a clear idea of what boundaries were.⁷⁶

Asked if she had any regrets about becoming an interpreter, this interviewee replied:

The one regret that I have is that we have a profession with no career opportunities. So I've [many] years of experience, I have trained interpreters, I have done all sorts of things, I mentor, I've done loads of stuff. But the day that a new interpreter qualifies they earn the same as I do, and there is no status and no recognition. I actually earn less when I'm training than when I'm interpreting. When I'm training you get paid a bit less plus you've all the preparation and the marking time which doesn't get paid. So that would be a big regret, that I'm stuck in that kind of scenario here in Northern Ireland, because I would've loved to have worked in an academic environment with deaf academics, that would've been my dream. Those kinds of opportunities aren't available in Northern Ireland so we are generic

⁷⁵ *Id.* at 21.

⁷⁶ IS 6, pt. 1, p.4.

interpreters, we do a little bit of everything, all of us. We don't have the choice of specializing in anything, and that's just the way it is. That's the only regret that I have.⁷⁷

As the preceding section reveals, sign language interpreters recognize their limited quantity as a problem for the entire community, not just deaf patients. Part of the problem has to do with a lack of training for work in the health care setting, and part of the problem has to do with the reluctance of either deaf patients or their health care providers to call for an interpreter. Problems like "white coat anxiety," the use of family members in lieu of interpreters, and deaf people's concern about boundary crossing require greater reflection and examination.

C. Health Care Provider Interviewees

Health care providers added an interesting insight to the role of the interpreter in the health care setting. For example, a fourth-year medical student fluent in BSL encountered an ethical dilemma in an interpreter training program when the answer he saw on the deaf patient's hands did not match what he heard from the interpreter:

It was a mock scenario for the interpreter-training programme. There was a deaf patient, and it was someone I knew quite well. So I was able to understand him very well, and I asked my question. The deaf patient signed back his answer, and I listened to the answer of the interpreter. The answers were very different things, and what the interpreter had voiced didn't match the question I'd just asked. So it was a bit of an ethical dilemma, I didn't know what to do, so I just asked my question all over again.⁷⁸

Asked what he would do about this problem in a real-world setting, the medical student said,

It would be hard because they are an interpreter. I'm not an interpreter. They know more than me, they know a lot more about sign language. So, it's hard for me to

⁷⁷ IS 4, p.5.

⁷⁸ MS 9, p.8.

give them any form of feedback, but I know what they voiced over was wrong. It would be hard for me to tell them that.⁷⁹

Told that American doctors are obligated to pay for a sign language interpreter, the same student fluent in BSL blurted out, “Oh, that’s awful.”⁸⁰ He went on to say that even though the National Health Service pays for the interpreter, doctors are still “reluctant to go through the whole rigmarole of booking an interpreter and I think they sometimes don’t really realize how necessary it is.”⁸¹ Part of the problem, as this interviewee put it, is the difficulty of coordinating the schedules of both the interpreter and the doctor:

The interpreter could come at certain times but the doctor doesn’t want that. He’s a very busy consultant. He has to see a lot of patients in the day, and if his ward round is right now, he needs to see that patient right now. You would nearly need the interpreter sitting there all day for an in-patient because you never know when the doctor’s going to come. So, for a doctor who has a lot of patients in a hospital, they have got to book an interpreter, and the interpreter can come at maybe four o’clock tomorrow, but [the doctor] might have a million other things happening in between now and four o’clock tomorrow. So, he doesn’t want to guarantee [the interpreter] will be there at four o’clock tomorrow. So, that’s a problem, fitting in the interpreter with [the doctor’s] schedule. I’m sure if there was sort of an interpreter wandering around a hospital and the doctor could click his finger and get the interpreter when he wanted, right there, I’m sure the doctor would be willing because it makes life a lot easier for them as well.⁸²

Asked if he needed an interpreter, who he would call, a general practitioner demonstrated some cultural competence in his answer:

⁷⁹ *Id.*

⁸⁰ *Id.* at 14.

⁸¹ *Id.*

⁸² *Id.*

Well, I would probably ask the patient if they have a [preferred] interpreter, and if not, I would ask the social workers from the disability team and ask them [to] phone them and ask them. There are social workers who work with children and families, with the elderly, with people with disability, with people with sensory deprivation or sensory problems. So there are social workers who work with the deaf, and I think there are signers who volunteer to help, if they know that one of their clients is going to [see] the doctor, they may try and arrange to be free to go with them.⁸³

Asked if doctors are more willing to take the responsibility to make the call for an interpreter, or if they would count on the deaf person to make the arrangements, a general practitioner indicated his understanding that sometimes a deaf patient's request for a family member to interpret would be inappropriate:

It's very variable, I think. You might get a family member coming along and signing. We organize reception to phone up and see if somebody could come down and sign. I don't think about that, I have to admit, and also we've got patients who come and lip-read. We had a recent one where I had to insist that even though the father seemed to be happy for [his] son to interpret, because of the nature of what we were going to be talking about, I felt that it was not appropriate, and we had to get an actual professional interpreter in.⁸⁴

Asked why deaf people are walking out of a doctor's office not satisfied with the communication between patient and doctor, a second-year medical student replied, "I don't know, I'm not sure whether [an interpreter] is mandated here. I think maybe it's optional to have an interpreter present. So maybe that's why, I'm not sure, I'm honestly not sure, I don't know."⁸⁵

As the preceding section shows, health care providers range from those who are clueless about the need for qualified interpreters to those who demonstrate some cultural competence in understanding

⁸³ MS 11, p.4.

⁸⁴ MS 7, p.12.

⁸⁵ MS 10, p.4.

that deaf patients need to have a say in retaining an interpreter, and that family members should not be interpreting for their deaf relatives. We now turn to the third theme that emerged in the interviews: the influence of the interpreter on the communication dynamic between patient and provider.

THEME 3: INTERPRETER INFLUENCE ON THE COMMUNICATION DYNAMIC

The final theme is the influence of the interpreter on the relationship between the health care provider and the deaf patient. While the presence of an interpreter provides communication access for both provider and patient, it does alter the dynamic of the relationship.

A. Deaf Interviewees

A deaf interviewee explained:

It's a massive Catch-22. It's just so unfortunate because whenever you communicate with somebody about anything you want to speak directly to that person. Why would you want to go through someone else, you know? Yeah, it's a funny paradox. While the interpreter facilitates communication, at the same time it provides a barrier in a way, you know?⁸⁶

The work of introducing the interpreter into the relationship between the health care provider and the deaf patient is shaped, in part, to the provider's lack of knowledge on the proper use of the interpreter. For instance, a deaf interviewee recalled, "I would sit [the interpreter] next to the doctor, facing me. At first, the doctor panicked. I would explain to the doctor how to use an interpreter and how the layout of the room needs to be before we proceed with the actual appointment."⁸⁷ Doctors in Northern Ireland typically allot ten minutes per individual for an appointment, and the preliminary explanation consumes a considerable amount of the face-to-face time with the doctor.

Other deaf interviewees offered a similar description of their introduction of the interpreter to a new health care provider. "If it's

⁸⁶ DS 25, p.16.

⁸⁷ DS 30, p.10.

the first time with [the] doctor, I'll always say, 'When you're talking, please speak to me, and please don't look at the interpreter. The interpreter is invisible, please don't talk to them.' I find with consistency the doctor will always look at me."⁸⁸ Another interviewee suggested,

The doctor will look at me, because I set it up, I will make sure. I will explain and introduce the interpreter to the doctor, and explain that the interpreter is there to translate. I ask the doctor to talk to me directly, and if they don't, then I will interrupt and ask the doctor to speak to me.⁸⁹

B. Interpreter Interviewees

Sometimes the doctor focuses on the interpreter and not the deaf patient: "I think a big part of it a lot of the time is, I don't know whether it's because there's an interpreter present but the doctor doesn't look directly at the deaf person, so the deaf person doesn't always say as much as they could."⁹⁰

An interpreter recalled at least one health care provider realizing the benefit of having a sign language interpreter in the examining room:

If they really want to get a full diagnosis, I mean I can remember like years ago going in with a deaf man, and it was the first time this deaf man had quite a serious medical condition. Somehow I ended up interpreting for him, and at the end of the interview, the doctor said to [the patient], "Please, please never come back here again without an interpreter because I have got a proper medical history from you for the first time in your life. I've been treating you all this time and I didn't really understand your condition."⁹¹

While the deaf patient's choice of an interpreter is important, equally important is the trust between the interpreter and the health care provider:

⁸⁸ DS 4, p.9.

⁸⁹ DS 17, p.12.

⁹⁰ IS 6, pt. 1, p.10.

⁹¹ IS 4, p.15.

I think too often we see people asking about, you know, deaf people choosing their interpreter, and that sense of trust is obviously very important and people always talk about that. But we don't really talk about the other aspect of that triad, of the trust between the interpreter and the professional, the doctor or the clinician or whoever it is, because that's equally important. You know, you can get on really well with your deaf person but if the relationship between the doctor is filtered by somebody that they're not that keen on or find jarring whenever they're working, then they project that distrust onto the deaf person. So that's where I think the relationship between the interpreter and the doctor is equally as important.⁹²

Some interpreters are finding it necessary to become more visible in the consultation between the health care provider and the deaf patient, crossing a boundary that they otherwise would not cross and becoming an advocate for the patient:

I think, the way interpreters are trained, and I'm sure it's the same in America, in the ideal world you are supposed to go into the doctor's surgery beforehand, explain to them the way it all works, and set up the seating arrangements. But whenever there's only ten minutes per doctor's appointment the doctor doesn't want to take that time. You can understand that because you don't want the deaf person to lose their time, but it does mean that sometimes that can affect the dynamics and that's why sometimes interpreters do need to overstep certain boundaries, just to ensure that that clarification happens.⁹³

Another interpreter struck the same theme of being helpful to the health care provider, this time by being flexible in the medical setting:

It's two-way. It's not "I'm here for them, not for you"; it's "I'm here for you and you," and at the end of the day, my aim is to make sure the information [from the

⁹² IS 5, pp.8-9.

⁹³ IS 6, pt. 1, p.6.

health care provider] is completely clear to the deaf person, but also [make clear] to the professional what that deaf person is feeling, suffering, whatever it is. How I do that? Being flexible. I know we have a code of ethics, yes, but I think sometimes ours is very, very fixed, and we have to be flexible in how we work, because at the end of the day, I'm employed for the deaf person and for the professional. The aim is communication would be as clear as it is for a hearing person with another hearing professional. If I walk away [and] they're completely lost as to what's going on, I've failed in my job.⁹⁴

Communication is a two-way street, with the interpreter as facilitator, which means the interpreter serves as a bridge for *both* parties and does not belong solely to one party or the other:

I got fed up [with] doctors saying to the deaf person, "Oh, well, you've brought *your* interpreter." I'd say "No, actually I'm here to interpret for both of you." [Interpreting] is covering them both: the doctor needs to be able to communicate with the patient, it's not just that the patient needs to know what is going on.⁹⁵

Asked if he saw an age differential in working with deaf patients, an interpreter replied in the affirmative:

I've found [age] to be the biggest factor, because generally the older generation are a lot more reliant on the interpreter and they think of the interpreter [as] the font of knowledge, whereas the younger deaf people, who've been brought up using interpreters and know the role of interpreter, seem to understand the interaction better. They are more able to ask the additional questions or to ask for clarification, whereas the older deaf people would just tend to look at me with a lost expression on their face, as if to say, "Help me."⁹⁶

An interpreter serves as a cultural mediator in some situations with the health care provider:

⁹⁴ IS 7, p.10.

⁹⁵ IS 1, pp.16-17 (emphasis added).

⁹⁶ IS 6, pt. 1, p.14.

There's always the deaf person that's going to sit there and nod and nod and nod because the doctor is talking to them, they're nodding just to say, "I'm listening," but the doctor's going to take that nod as being "I'm understanding," and it's about explaining the difference between the listening and the understanding of it, and that's where I think the interpreter has to step in, and not ask the questions but more so to say, "Yes, but can we have additional clarification?" The deaf person might not realize that there's more to know.⁹⁷

C. Health Care Provider Interviewees

A second-year medical student expounded his view that the sign language interpreter has a positive influence on the consultation between the doctor and the deaf patient:

I don't think [the interpreter] would be a hindrance, no, because I think there's more of a barrier if communication isn't there, and I think if the interpreter's there, there's more chance of being able to establish good communication with the [patient]. It's really important to talk to the deaf person. The interpreter's there as a service for them, but they're your patient, and I think that's really important. So I don't think [the interpreter's] presence should be a barrier to the communication. If anything, it should enhance it.⁹⁸

Yet, while one health care provider is aware that the lack of an interpreter impacts the quality of health care for deaf patients, he continues to rely solely on written notes and lip-reading:

So by lip-reading and by writing, that's primarily how we communicate, and in fact I don't think I've ever had use of a signer, well only with that one patient have I had a signer come with them. Now what that probably means is that deaf people are not accessing health care as easily or as well or as beneficially as hearing patients

⁹⁷ *Id.*

⁹⁸ MS 10, p.15.

are. So I am sure the quality of care that they receive is inferior to what hearing patients receive, and I'm also sure that most doctors feel disadvantaged with deaf patients and struggle to communicate. So therefore they restrict how much they try to say, and the amount of information that's communicated will be less than with hearing patients since the consultation revolves around good communication.⁹⁹

Asked about the impact of written notes on the doctor's time, this doctor replied, "Oh it takes much longer to have a consultation with a deaf patient."¹⁰⁰ He continued:

You know, in all honesty, we don't have very many consultations with deaf patients. It's really quite an uncommon thing. Now that may be because deaf patients are slow to come to the doctor because they realize that it's a difficult dynamic, and so therefore they don't come as quickly as patients who are hearing.¹⁰¹

The same doctor acknowledged the limitation of written notes:

Interviewer: Let's say, if writing doesn't work, and lip-reading doesn't work, what do you do then?

Doctor: That's where you need an interpreter, yeah. That would be what I would do. Most of my communication has been by writing. I would write a question and they would write the answer, and I think that's how most doctors do it.

Interviewer: Do you notice a difference in their rendition of English, you know, how they phrase things and grammar?

Doctor: Yes. Often when [the patient] writes, their grammar is not good, but then that is also true for many of my patients who come from more disadvantaged backgrounds, and they don't read or write a lot, and so their grammar and their spelling can be poor.¹⁰²

⁹⁹ MS 11, p.2.

¹⁰⁰ *Id.* at 3.

¹⁰¹ *Id.*

¹⁰² *Id.* at 4.

Asked if the interpreter stuck out like a sore thumb in the examining room, a medical doctor stressed invisibility as a positive factor in the encounter between doctor and patient: “I think a good interpreter almost becomes invisible, you know, so it’s not a problem at all.”¹⁰³

A doctor recognized the change in the communication dynamic when working with a sign language interpreter:

You’re very conscious there’s a barrier even with an interpreter, you’re very conscious that it’s slow. That you don’t have the immediacy of the communication that one would normally have, with [hearing] patients. I suppose you need to be careful about the emotion that is coming across or not coming across, or that is being misinterpreted, you know, because I think, for example, communicating with patients who don’t speak English or patients who are deaf, sometimes a facial expression is more to do with communicating with the interpreter than it might be communicating with me. You know, it’s the non-verbal stuff as well.¹⁰⁴

A fourth-year medical student fluent in BSL agreed:

I think [the interpreter] definitely does change the dynamic. It depends if the doctor knows how to use an interpreter. For doctors who don’t have [deaf] awareness, I think these doctors tend to talk to the interpreter, might not listen to the deaf person as much, get distracted by the interpreter. I think some doctors don’t even comprehend the fact an interpreter is just saying everything the deaf person’s saying. Sometimes they think the interpreter is speaking for them. It’s always going to go through the interpreter, so although an interpreter is just interpreting and passing information, their view of the world and their perceptions are always going to slightly influence the way they portray the [patient’s] language. If you have a deaf patient and five different interpreters, I think you wouldn’t obviously get a word-for-word transcript,

¹⁰³ *Id.* at 3.

¹⁰⁴ MS 7, p.5.

which would be the same for the five different interpreters. So there's always going to be some sort of change in the way the language is portrayed, but you can't do anything about that, that's just the way it's going to be.¹⁰⁵

Asked about the propriety of a family member serving as an interpreter for the deaf patient in the health care setting, another student replied:

The other thing that we were told as well, which I felt was very interesting, was that maybe, for a lot of the times, it might not be ideal to have a family member there. A lot of the times a medical setting might be more difficult if it's a family member because they might abridge things or, you know, try and soften what's being said to you, you know, stop you from getting hurt. Whereas you need to hear everything that's being said in a medical setting, you want to know, so it might be better to have an independent interpreter in that kind of setting.¹⁰⁶

Reminded that a family member may inhibit the deaf patient from divulging certain information, the student recalled:

You know, even for a young girl going to the doctor about anything, birth control, any of those kind of things, you wouldn't want to be talking about those kind of things in front of your parents. It's just too private.¹⁰⁷

Asked if it is important for the interpreter and the health care provider to work together as a team, a medical student replied:

That's what I think, yeah. Or at least the doctors need to be provided with some basic understanding of how to work with an interpreter. There's a lot of emphasis on teaching doctors basic sign language and deaf awareness and things like that, and I think teaching them sign language and everything is wonderful and

¹⁰⁵ MS 9, p.4.

¹⁰⁶ MS 10, p.16.

¹⁰⁷ *Id.*

brilliant, but I think it would be even better to teach them how to work with an interpreter.¹⁰⁸

CONCLUSION

At the end of every interview of the deaf subjects, I asked each person, “What would you say if you had an opportunity to speak to a group of health care providers?” Almost universal was the response: “respect.” Deaf people want to be validated as a cultural and linguistic minority whose sign language is accepted as a mode of communication on par with spoken English. While they recognize that hearing providers cannot become fluent in sign language, they insist that providers achieve at least a minimum of awareness about deaf culture, the frustrations and barriers facing deaf people in the health care setting, and the utmost necessity in many cases for the services of a sign language interpreter to ensure full and effective access to health care as required by the UNCRPD.

The interviews yield a list of “best practices” that ought to guide health care providers working with deaf patients and sign language interpreters:

- Ask the patient what he or she needs in terms of communication
- Face the patient, look at him/her in the eye, and speak directly to the person
- Provide extra time in the examination room
- Check with the patient regarding written instructions or reports—do not assume they understand without checking
- Use visual aids in describing medical terms or conditions
- Ask the interpreter how he or she should be placed in the examining room
- Be open to an interpreter’s feedback about what works for the interpreter
- Work with the interpreter referral agency ahead of time to maximize the likelihood of securing the services of a sign language interpreter

¹⁰⁸ MS 9, p.4.

- Refrain from using a family member to interpret unless it is an emergency and only on a temporary basis
- Rethink their assumptions about deaf people and sign language—be open to the variety of communication needs
- Deaf need to develop self-advocacy skills, and to learn their legal rights
- Evidence from medical providers points to violations of UNCRPD, use of written notes, deaf not coming in as regularly as hearing

We now close by going back to Article 25 of the UNCRPD which requires Northern Ireland to provide persons with disabilities with the same range, quality and standard of free or affordable health care and programs as provided to other persons; to require health care providers to provide care of the same quality to persons with disabilities as to others; and, to prevent discriminatory denial of health care or health services on the basis of disability. The study attempted to assess the extent to which Northern Ireland complies with the UNCRPD, and the interviews suggest that the record is mixed. Of notable success is the course offered to the medical students at Queen's University Belfast where the students learn about deaf culture, improving their ability "to provide care of the same quality to persons with disabilities as to others," as required by the UNCRPD. However, development of cultural awareness in older providers and increasing the pool of sign language interpreters are more difficult issues to address. The study suggests the need to devote resources to help train medical interpreters and provide health care providers with cultural awareness training. Although we have some ways to go, the future is bright.