**Jen**

Great. Okay, well, I'm going make sure that it's actually two o'clock I'm going to get started. I guess I should just let you all know who I am. For those of you who don't know me, I'm Jen Goulden, the past president of Braille Literacy Canada, and I have the pleasure of introducing our second speaker this afternoon, Dr. Frances Mary D'Andrea, and I'm going to quickly read her bio just so that I don't leave anything out. I met FM in 2012, at the ICEB General Assembly in South Africa, where we also went to a safari and got to pet a lion cub, which was pretty exciting. So okay, on to the official things. And what's going to happen is, I'll read the bio, and then I will hand things over to FM and then when her talk is finished, around 2:30 or so, and we'll have some Q&A and I don't want to give anything away, but possibly, another door prize. So with that, here we go:

Frances Mary D'Andrea, Ph.D., is an Assistant Professor of Practice at the University of Pittsburgh. Before joining the faculty at Pitt, she was an Educational Consultant specializing in literacy issues with students with visual impairments, and she was an Adjunct Instructor at several US universities. She was a teacher of students with visual impairments in various schools. From 1995 to 2005, she worked with the American Foundation for the Blind, AFB, and helped establish their National Literacy Center. She's a past chair of the Braille Authority of North America, (BANA), and she served as AFB's representative to BANA since 1998. She's currently the secretary of the International Council on English Braille (ICEB). She's the author of several textbooks, including the *Ashcroft's Programmed Instruction* in Braille. I don't know what my problem is, I'm sorry, apparently, it's Friday afternoon. *Unified English Braille*. Good thing I'm not doing the talk. She serves on numerous committees and national task forces related to the education of students with visual impairments. So that's a lot of stuff. I don't know how you where you find time to sleep, FM, but I'm going to hand it over to you now.

**FM D'Andrea**

Thanks. Thanks, Jen. And thanks, everybody, for inviting me. I love following Cay [Holbrook] because I always find Cay's talks so interesting and inspiring. And I would love to continue that conversation as well and enjoyed reading everybody's favorite contractions on the chat.

I have a PowerPoint up, but in the chat, there's a copy of my PowerPoint that you can download and follow along. But, because I only have a half an hour, I'll try to go over this as quickly as I can, because I really want to get to the questions.

My presentation is "How Many Braille Readers (And why it matters)". And this was a project that actually was started several years ago. This is not just my project at all, I just have the privilege of being able to share it with you all today. I want to acknowledge my collaborators in this: Dr. Rebecca Sheffield, Dr. Val Morash, Valerie Morash and Sarah Chatfield.

I also have to make sure I can advance the slide, okay. I also want to acknowledge the memory of our friend and collaborator, Val Morash who died a few years ago, suddenly in an accident. And it was a great, great loss to not only to our project, but to the field at large, because Val was intensely interested in braille, and was an amazing thinker and researcher.

Let me just tell you a little bit about this project. I have on this slide, "Everybody knows…", and then the question "Or do we?", because I think we see in certain statistics and numbers related to braille and braille literacy and braille readers that are just shared as common knowledge.

For example, on the next slide, I have three quotes that actually come from the kind of the mainstream press. One quote is "… advocates of the tactile writing system are wrestling with how to address record low braille literacy". That's from the *Associated Press Bulletin*, another quote was "In an environment where only ten percent of blind children receive braille instruction …", which comes from the *PR Newswire*. And a third quote, which is, "In 1970, more than half of blind American schoolchildren could read braille. Now only about 10% can.", which came from *The Economist*. We see these kinds of statistics shared widely. Not just in our fields, but also in the mainstream press and they are repeated over and over again, often without any attribution at all, as I'll get to in a minute. This kind of common knowledge, is also something that got us thinking.

The next slide, "How do we know… what we think we know?" because seeing these kinds of quotes over and over again, and it was interesting, that Rebecca Sheffield, who at the time was working at the American Foundation for the Blind as one of their research folks. And Val, who was working at Smith-Kettlewell, at the time doing research, and I was as an Educational Consultant at the time and doing textbooks and lots of things. It is funny that the three of us had all started kind of collecting information about these statistics and, and the source of them. And at some point, I actually don't even remember how the three of us got together and said, you know, we really should do a project about this. Where did these numbers come from? Where did these statistics come from? How do we know whether that's correct or not?

We started a project to investigate this so called common knowledge. So our research questions were, "How many `braille readers` are there in the United States?" Another question was, "What percentage of `people who are visually impaired` `read braille`"? And I'll tell you why these words are in quotes in a minute. But our underlying question was, "What evidence do we have to back up these numbers"? And these terms, braille readers, read braille? That's kind of an essential question. And as we got into our project, it led to some really interesting results.

So let me tell you first, what our process was what we did to kind of answer this question. And we did a lengthy and systematic literature search, we did in electronic search. And this is I'm giving you just a really short view of the process. We actually have submitted this article for publication, and it was accepted so it will be published in the *Journal of Visual Impairment & Blindness* at some point in the future, and I go into a lot, we go into a lot more detail about our research methods in that article. I'm just going to give you kind of the capsule view today.

We did an electronic search of all the records that we could find to 2015. And then we did a second search, from 2015 to 2019, coming up with 4,383 sources. We looked at existing reviews, and then we did a hand search, especially for older materials.

We looked at documents, the *Journal of Visual Impairment & Blindness*, for example, has been around in various names for, it was the, I think, *The New Beacon* and the *Outlook for the Blind*, going back to 1907. We looked at before there was an AER, there were two separate organizations, AAWB and AAIB, and we went back to their convention publications, going back to the 1800s. We really wanted to find any kind of research from historical up to the present that reported actual reading rates or any kind of statistics.

We looked at all the titles and abstracts, we deleted the duplicates, and we created this huge spreadsheet, and did a hand search of even older materials. We looked through all of those sources, and we retained 95 that actually reported rates of braille literacy.

The next slide to talk about; what were those 95 sources that reported a braille literacy rate. Of those 95, there were 39 that affirmed some braille literacy rate, but it didn't have a source. It didn't say where the numbers that they were reporting came from. 19 of the sources cited the American Printing House Federal Quota Census, which we'll talk about more in a minute. Nine of the sources that we found, cited one of those 39 articles, but again, those articles didn't have any sources with them. Four cited a document that had been written by the National Federation of the Blind, that reported some rates, and only seven cited primary source research, where the questions were, "How many braille readers are there?".

Let's take a look at what those primary sources were. On the next slide, I have them listed chronologically. We're going back to 1935; there was a study done by Heyer that looked just at the state of New Jersey, and of the 2,500 people surveyed, one third reported that they were "literate" in raised type. If you have to think about what 1935 was like, it was the *English Braille American Edition* contracted braille was only a few years old at that point, because it wasn't until 1932 that it was actually adopted; *English Braille American Edition*, the 1932 edition, which was different from the 1959 edition, different from the 1994 edition. At that point, that's about a third in New Jersey.

A study done in 1941 of New York schools, recorded of the students in the New York City Schools, elementary schools there 84 who were in what they called sight conservation classes at the time, and six were braille readers. Of the junior high schools, there were no braille readers. Then at the senior high schools, there were three braille readers. And again, that was 1941 in New York City.

A 1945 study from the New York Association for the Blind found that 28% of the people who were associated with the Lighthouse and then New York Association 28% read braille and 3% read New York Point or Moon Type. I know that there were magazines like the Matilda Ziggler magazine, published I think New York Point up until like 1960. There were other tactical codes that were still being used in the early part of the 1900s.

A study in 1960 by Bray estimated that "less than one sixth" of the National Library Service Regional Library customers read braille.

1964, Josephson reported about a third of people who were drawn randomly from state registers reported being able to read braille.

1979, Berkowitz reported that braille is used most frequently as compared to other media by only two percent of readers with NLS eligible print limitations.

A study by Chris Craig in 2002, looked just at the state of Missouri, reporting about 19%. So we see a real difference from state to state, and from study to study, about how the statistics are gathered, and how they were reported over time.

The next slide I talked about issues with primary sources and the citations. First of all, of those primary sources, only three include national level data or estimates. The others were state level, like the state of Missouri, or the city of New York, or the state of New Jersey. Most of these primary sources, as you probably also noticed, are now decades old. The most recent being 2002, which believe it or not, was almost 20 years ago, I know I have a hard time believing that.

The other thing we found in looking at all of these articles was that the methods were not always clear, like what methods they use, or they weren't rigorous. Sometimes they were just telephone surveys or, going back a slide, there was a survey that drew randomly from state registers, that's not really a rigorous collection of data.

The other thing we found is that some of the citations are extrapolations, or estimates that are based on incomplete or old data. For example, in 1996, the American Foundation for the Blind published in the *Journal of Visual Impairment & Blindness*, a demographics report, and it was on the AFB website for a while I was working at AFB at the time. And that demographics report in '96, was based on the 1979 Berkowitz survey. So in 1996, they're using data that were already 17 years old. And that had been done by a study that I think was done, I think that was the telephone survey of just NLS users. So that was just a subset of people.

The other thing that we found is that some of the citations were based on the American Printing House, the APH, federal quota statistics. And I should also say that this project that we have been doing is only looking at the United States. At one point, we thought about whether we should add Canada or other countries, and it was just too big, there were too many; the spreadsheet was already complicated enough. We decided that we're just going to focus just on the on the United States. I'd really be interested in knowing if Canada had any statistics like this.

So anyway, as I was saying, some citations were based on the APH federal quota. When you look at the APH statistics over time, the categories changed in 1985. So you can't really compare populations from the early 60s, and so on to anytime after 1985 because the categories aren't the same.

The other issue with the APH federal quota census, is that, again, that's only a subset of people. For those of you who are not familiar with the federal quota, the American Printing House, does a census each year of how many students who are enrolled in a program that's 12th grade or below, even if they're adults, but if they're in a program that's 12th grade or below who are legally blind, or they have a new category that captures the functions at the level of blind, I think is what they call it. I don't remember the exact words right now. Again, there's just a subset of people. And APH is very careful to say that their quota data should be used really carefully. There's a statement on the page website called appropriate use of federal quota census data. It states that the specific purpose of the annual federal quota census is to register students in the United States in outlying areas who meet the definition of blindness and are eligible for adapted educational materials. "Statements regarding student literacy, use of appropriate learning media, and students taught in a specific medium cannot be supported using APH registration data". So we have to be really careful when we're using the APH census because that's not the purpose of it, and it's not to be extrapolated in that way. And in fact, if you look at the APH data, they have the census data reported in different ways; they collect primary reading medium, secondary reading medium, they have a very large category of what they call pre-readers, those kind of students in the emergent literacy level, and also what they call non-readers, for whatever reason that students are registered in that way. So depending on how you look at the data, you get different statistics anyway, even though as I said, they're not designed to give information about how many people are using particular media.

Here's the other issue that came up that was really important. That made it especially difficult to capture any kind of statistics in a clear way. And that is, there were no clear definitions at all, as to what a braille learner was, or a braille reader or a braille user. And that's why when I showed you all the research questions, we had to put those terms in quotes. They were search terms, but we broaden the search terms as much as we could, because what we found was, does a braille reader mean someone who's a proficient braille reader, or someone who just uses braille reading for some purposes and not others? Do they use braille exclusively? Do they use braille primarily? What if they use both braille and print? What if they've been taught some braille but they tend not to use it for other things? What if they get all of their instructional materials in braille? So there was no clear definition, there was no consistent definition of what braille literacy even meant, and what a braille user, reader, or learner was; in fact, there were no clear definitions even as far as what we meant by blind people or visually impaired people.

When we looked at sources such as the US Census, the Washington Group on Disability Statistics, the National Center on Health Statistics, the World Health Organization, the Social Security Administration, and the OSEP, the Office of Special Education Projects, that that collects data through the federal law, IDEA, the Individuals with Disabilities Education Act. There was not one clear definition, there were a lot of definitions that were self-report. Or they were based on, kind of, functional activities, rather than like an acuity measure or something else. In fact, one of the articles we found by John Cruz and his colleagues, they did an analysis of 12 federally funded projects. They've noted that they were different questions on every single one of those for how visual impairments was defined. So even within the US federal government that you would think be trying to collect these data. There was no clear definitions, and the question of "Are you blind" was asked in a different way in all of these occasions. You can see how that could definitely lead to some issues when you're trying to find some comparative data when you're trying to collect data. That is clear as to who we're talking about, and how these data are used. We also found that a lot of it, the questions change depending on who was asking and for what purpose.

There we go. So overall findings, and then I want to get to the discussion. We really found there was no clear support for that 10% braille literacy rate statistic that we see all over time, we did not find any definitive or, frankly, even suggestive, support for that statement.

We found that the shifting definitions not only through the APH census, but through all of these other data collection sources, even at the federal level, made it extremely difficult, if not impossible, to compare rates and numbers over time. Even looking at those primary sources that I showed you earlier, from 1935 to 2002, there was no clear indication at all as to how many people were braille readers and how those numbers were collected.

Our third finding really is that it's unclear if there's a documented decrease in braille usage because to some extent, it's easier now than ever to produce braille or to create braille, or to use a portable braille device, a refreshable braille device to access materials and information using braille.

At the same time, there's also been a rise in speech access. So does one outweigh the other? Or we don't know and it's really difficult to be able to tell. There doesn't seem to be any support for the statement that in the '70s over half the children learned braille, because we don't have that data. We don't know what "learned braille" meant, because there's no definition for it. I know that sounds really picky. But it's important to be able to have clear definitions if you're trying to count something. And because of the difficulty in the way these things have been defined and counted over time, it's difficult to come up with that. If there is a decrease in braille reading, as I said, we can't determine a rate or a cause of any such decline.

I'll be honest, some of these findings were quite surprising to us as a team, and we had a lot of conversations about it, the implications of it. In this discussion, we are proposing several things, and then I'll tell you about our call to action. The things is, when we don't have recent, especially recent, reliable sources of data to support any statistics, we have to be careful when we're providing numbers, whether it's in a research publication, or even in the mainstream media. What messages are we sending? How can we make sure that we're providing information that's accurate?

As a professional field, we shouldn't be repeating statistics without citations. We certainly should have some citations and we also have to be really careful about how we present information so that it's accurate.

The other thing we found is "how many braille readers are there?" is a really complex question. It's important to consider what we want to know and why we want to know it. We, just our little team, our thoughts are: it's important to have information especially for policy decisions. Because policy should be set on actual accurate data and not on as Rebecca Sheffield said, it was like a game of telephone, I don't know if you are familiar with that game, when you are kids and you sit in a circle and you whisper something into somebody's ear and then they whispered in the next person's ear, and it goes all the way around the circle. And you see whether it came out the same as it came in and it like never does. The question is complex for the reasons that I said, but we also want to make sure are we asking the right question?

And this is where we had our call to action. And that is first: we should use data responsibly. And we should be thinking about what is being reported. and for what purpose.

Again, if we're using data to support the need for resources, or for services, then we should really be capturing that information in a more consistent way. We really need to advocate for clear and consistent terminology and definitions.

We should advocate for consistent and rigorous data collection at state and national levels. One of the reasons why in the United States, the Cogswell Macy act that has been proposed by AER; maybe some of you are familiar with hearing about this through AER is so important because one we know already that in the United States, the numbers of children with visual impairments is undercounted through the IDEA reporting because states are only required to report primary disability and many of our kids have other disabilities as well. We already know that there are states that are reporting X number of children who are blind, but they're providing braille materials for three or four times that number of students. But it's not that that data is not reported anywhere because it's not required to be reported.

And for us, the more salient question is: Are the children and adults who could benefit from braille instruction are they actually receiving it? And that becomes an issue of capacity and of recognition, because the importance of braille literacy can't be undervalued, it's essential. And if we are undercounting, or if we don't have clear numbers, if we don't have a clear way of collecting those data, are we actually doing the best we can to make sure that folks are receiving the braille instruction that they could benefit from? Natalie Martiniello and I have had that conversation, especially for adults very much.

Here's a question in the chat, you know, question is, what were the purposes of the articles? Were they trying to show the funding was being wasted on braille literacy? Or that their schools for the blind? You know, that's a really interesting question, Carrie, because some of the articles were more towards, like a fundraising sort of thing. That "see, we don't have enough Braille materials, therefore, you should be supporting our efforts" or, and other things were possibly related to not being not providing braille.

For example, manufacturers, or folks who are the pharmaceutical companies in the EU, they're required to put braille on packaging. So if we are sending a message that braille is not important, or that not very many people use it. Are we then again, undervaluing the benefits of braille for people who could use it?

Alright, so that's my half hour. And I'm up for questions. Somebody else said, we're living in an era of widespread misinformation. Yeah.

**Jen**

Before we get to the Q&A, I just want to take this opportunity to thank you very much for coming and doing this presentation. I found it both informative, and actually encouraging because as a braille reader, I've always really hated that statistic. Because people in the field and people, even the media in Canada, use this statistic a lot. It always came across to me like, wow, only 10% of people read braille, so it's not really that important. Of course, we all know that braille really is important. I think this is very, very good information for all of us to have. And I'm so excited that you guys did this research.

**FM D'Andrea**

Thanks. The last slide, I have our contact information if you want to send us email Rebecca Sheffield. And me and Sarah, we want to thank a APH and AER for letting us look at their archives. And thanks to Eric Caruso and Daisy Lee, who were research assistants.

**Jen**

Awesome. Thank you. Sorry, I didn't realize you had a last slide.

Natalie, are you wanting to do a door prize? Well, I'm gonna hand it over to you!

**Natalie**

Thank you, Jen. And thank you, Frances Mary. I am very excited about this research. BLC gets this question a lot: How many braille readers are there? What's the braille literacy rate? And we try to kind of go through what you very eloquently went through today. One of the questions I'll have for you is, you might have mentioned this at the beginning, but whether this is published yet because I'd love to send this as a resource in the future when we get this very common question.