Promoting Dignity through Design: A Grounded Analysis of Stakeholders' Views on the Role of Disability Organizations in Inclusive Design

by
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Abstract

Inclusive design promotes the involvement of users with diverse needs in the design process. The possibility of disability organizations collaborating with businesses to enhance accessibility through inclusive design was explored in this major research project. Open-ended interviews were held with twelve participants representing interactions with disability organizations as clients, employees, volunteers, supporters, or business associates. The data were gathered and analyzed using a grounded approach. The analysis revealed the complexity of accessibility and the value associated by the participants with dignity. A model focused around dignity and a potential application was proposed as a supportive tool to illustrate the concepts further. A core idea proposed by this research is that design, when directed at promoting the dignity of the users, could enhance their experience and create more inclusive systems.

Key words: disability, dignity, inclusion, inclusive design, disability organizations

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And to my family who lived this research each and every day

-- thanks from the bottom of my heart!

Dedication

To my Mom

Table of Contents

List of Tables

List of Figures

1 Introduction

“We cannot solve our problems with the same thinking we used when we created them.”

~ Albert Einstein

I began this project with one way of thinking and now leave it differently and changed. The journey commenced with my perspective as a professional web designer, tempered by my personal indirect lived experience of disability and refined by lessons learned in the inclusive design program. Along the way, I encountered a wider inclusive consideration of human rights as a design factor. I now have a greater appreciation of the nuances of accessibility, disability, and what it means to be an inclusive designer.

1.1 Rationale

The demand to design products and services to accommodate the needs of an aging and disabled population is growing. This demographic forms an estimated population of 1.3 billion, constituting an emerging market the size of China and controlling over $8 trillion in annual disposable income (Donovan, 2014). Further, in Ontario there is a legal requirement, The Accessibility for Ontarians with Disabilities Act (AODA) (Government of Ontario, 2005a), that mandates businesses comply with standards in customer service, employment, information and communications, transportation, and

design of public spaces. Businesses often have limited in-house resources to be able to practice design research to comply with the regulations or to go beyond standards to investigate true user need.

Inclusive Design addresses the need for everyday products to be accessible and usable by as many people as possible without the need for special adaptation (Hussain, Case, Marshall, & Summerskill, 2013, p. 147). Inclusive Design has also been called design with a purpose specifically toward greater inclusion and equity because it does not advocate specialized accommodation of disability. It champions the design of products and systems that consider the needs of outliers, and therefore can even be a catalyst for social and systemic change. It promotes the involvement of the user in the design process (Treviranus, 2014).

Disability organizations on the other hand, have expert knowledge of the challenges of living with disabilities. Their expertise appears under-utilized and untapped in the marketplace, especially for co-design and testing of products and services on a revenue-generating basis. Providing co-design research services could be an opportunity for disability organizations to turn the perceived disadvantage (disability) of their members into an advantage (remuneration) for them.

This study chronicles a journey to investigate a sustainable business model for disability organizations to use inclusive design. My study initially proposed to investigate a sustainable business model for disability organizations whereby these organizations act as service providers of inclusive design and testing services to businesses that need this expertise. As the research evolved, I rephrased the question to ask instead: How can inclusive design support the work that disability organizations are already doing?

1.2 Research Framework

I used a grounded approach. I consulted a range of representatives from disability organizations, disabled persons, researchers, accessibility specialists, designers, and disability employment specialists familiar with disability issues. Twelve participants in total were interviewed either in person, by telephone or Skype as to their thoughts and perspectives on the potential design power of disability organizations.

Using an interpretive framework, and understanding that certain power and social relationships within society are detrimental to marginalized groups and individuals (Creswell, 2013, p. 20), the design response of this research was to identify both common themes

among participants and a suitable design project to help rectify barriers described in the interview process.

As a researcher who is co-constructing knowledge centered on disability with my participants, it is helpful to provide a self-reflection for the reader to understand how I am situated in the research. In the world of disability, I am in "the space between" as neither an insider nor outsider (Corbin Dwyer & Buckle, 2009). Although not disabled myself, disability has been interwoven into my life as an indirect lived experience, through close family members with disabilities. My experiences as a child with my grandfather, who had a physical disability, and with an aunt, who had a cognitive disability, are described in Appendix A – Self-reflection on Disability Experience.

1.3 Background

1.3.1 Disability Organizations

Disability Organizations are defined in this research as "non-governmental organizations that provide services such as employment preparation and training and related services for persons with disabilities". (Levesque, 2012). Disability organizations must apply for charitable registration status to become eligible to be income tax exempt and to issue official donation receipts to donors (Canada Revenue Agency, 2007). Recent research in the UK indicates

that donors choose charities based more on personal taste and preference, rather than on need (Breeze, 2013). In addition, an American study indicates that non-profit organizations are under considerable pressure to under-report or short cut administration expenses to please funders (Goggins Gregory & Howard, 2009).

There are two types of disability organizations as defined by Hutchison, Arai, Pedlar, Lord, & Yuen (2007). The first is non-user led, where there is not a strict policy to include people with disabilities in the leadership and the constituents are referred to as “clients”. The second type is user-led, where there is a strict policy to include people with disabilities in the leadership.

The participants in this study were predominantly associated with non-user led disability organizations; however, the discussion and sample web application arising from this study could be of interest to user-led organizations as well.

In 2006, people with disabilities had lower participation in the labour force by 28 per cent, lower income levels, and lower educational attainment than people without disabilities (Kemper, Stolarick, Milway, & Treviranus, 2010).

Given these statistics it is no wonder that disability organizations try to help bridge the gap to help people with disabilities cope. As the

population ages, the need for increased formal and informal support networks could be expected to increase (Binette Charbonneau & Knight, 2012).

1.3.2 Definitions of Design and Inclusive Design

Lauer and Pentak (2000) describe design as the “opposite of chance” and provide three simple non-sequential stages for the design process:

1. Thinking: What is to be done and accomplished?
2. Looking: Observation and evaluation and
3. Doing: Prototyping.

Many similar definitions exist under the name “inclusive design”. The British Standards Institute defines inclusive design as “the design of mainstream products and/or services that are accessible to, and usable by, as many people as reasonably possible…without the need for special adaptation or specialized design.”(University of Cambridge, 2013). The University of Cambridge proposes the following three dimensions of inclusive design: user centered, population aware of a wide range of capabilities, and business-focused to provide sustainable and profitable products.

The Inclusive Design Research Centre (IDRC) at OCAD University in Toronto defines inclusive design as: design that considers the full

range of human diversity with respect to ability, language, culture, gender, age and other forms of human difference (Inclusive Design Research Centre, 2013). The IDRC's three dimensions are: recognition of diversity and uniqueness, inclusive processes and tools, and broader beneficial impact.

Broader beneficial impact specifically includes what is called a "curb-cut effect". This phenomenon refers to sidewalk curbs that were cut to accommodate wheelchairs, but had an overall benefit for strollers, shopping carts, and so forth (Treviranus, 2014). This study uses the IDRC's definition of inclusive design, especially with regards to focusing on a broader beneficial impact.

1.3.3 Disability and Accessibility

What is disability and what is accessibility? There are many definitions of both terms. The World Report on Disability ("The Report") characterizes disability as "complex, dynamic, multidimensional, and contested" (World Health Organization & The World Bank, 2011). The Report defines disability using the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001). This is a framework where disability is comprised of difficulty in one or more of the following three functional areas: impairments (problems with functions of the body), activity limitations (difficulties doing daily

activities or tasks such as walking), and participation restrictions (problems with involvement due to things like discrimination or transportation).

The Report emphasizes that the disability experience is unique to each person and results from interaction between health conditions, personal factors and environmental factors.

The Report also defines accessibility as “the degree to which an environment, service, or product allows access by as many people as possible, in particular people with disabilities”.

In addition, the Government of Ontario has a definition of accessibility on their website: “What is accessibility? It simply means giving people of all abilities opportunities to participate fully in everyday life” (Ontario Ministry of Economic Development, Employment & Infrastructure, 2014). Both definitions of accessibility work in the context of inclusive design. This research uses the ICF definition of disability.

1.3.4 UN Convention and Legislation

The Convention on the Rights of Persons with Disabilities (“the Convention” or “CRPD”) (United Nations General Assembly, 2006) is an international treaty that upholds the rights of persons with disabilities and recognizes that “disability is an evolving concept”.

Within the Convention “universal design” is defined as “the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaption or specialized design”. It is interesting to note that universal design is considered so closely tied to human rights that it is defined and promoted as an obligation under Article 4.

In addition to “universal design”, the word “dignity” is used, for example, “The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and to promote respect for their inherent *dignity”*.

Canada ratified the Convention on March 11, 2010 and it came into effect in Canada on April 12, 2010. The First Report of Canada (Government of Canada, 2014) details the progress that Canada has made in “upholding and safeguarding the rights of persons with disabilities and enabling their full participation in society”. In the report Canada details laws and measures it has in place, including the *Canada Act 1982 (the “Charter”)* and the AODA among many others) to safeguard the rights of people with disabilities. In addition to highlighting progress, the Report also states that challenges still exist

"including barriers to language and communication, learning and training, and safety and security".

Under section 15(1) of the Charter, "Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability."

An infringement of the above Charter would be a failure on the government's part, in purpose or effect, that would perpetuate the view that people with disabilities are "less capable, or less worthy of recognition or value as human beings or as members of Canadian society, rather than equally deserving of concern, respect, and consideration[1]."

[1] Egan v. Canada, [1995] 2 S.C.R. 513, [1995] S.C.J. No. 43 at para. 39 (Egan v. Canada, [1995] 2 S.C.R. 513, 2010)

2 Literature Review

I took a grounded approach to the research and describe the theory more fully in the methods section 3.1. Briefly, Grounded Theory was founded by Glaser & Strauss (1967) and is a research strategy that enables a researcher to create theories and observations from the data. Various branches of the theory have evolved and I am using the approach of Corbin & Strauss (2015) and Charmaz (2003) where the researcher co-constructs the data with the participant. Thus, with the exception of inclusive design, other bodies of knowledge were not known at the start of the interview process. The areas that emerged are design thinking and disability studies. Figure 1 depicts the overlap with disability organizations in the middle.

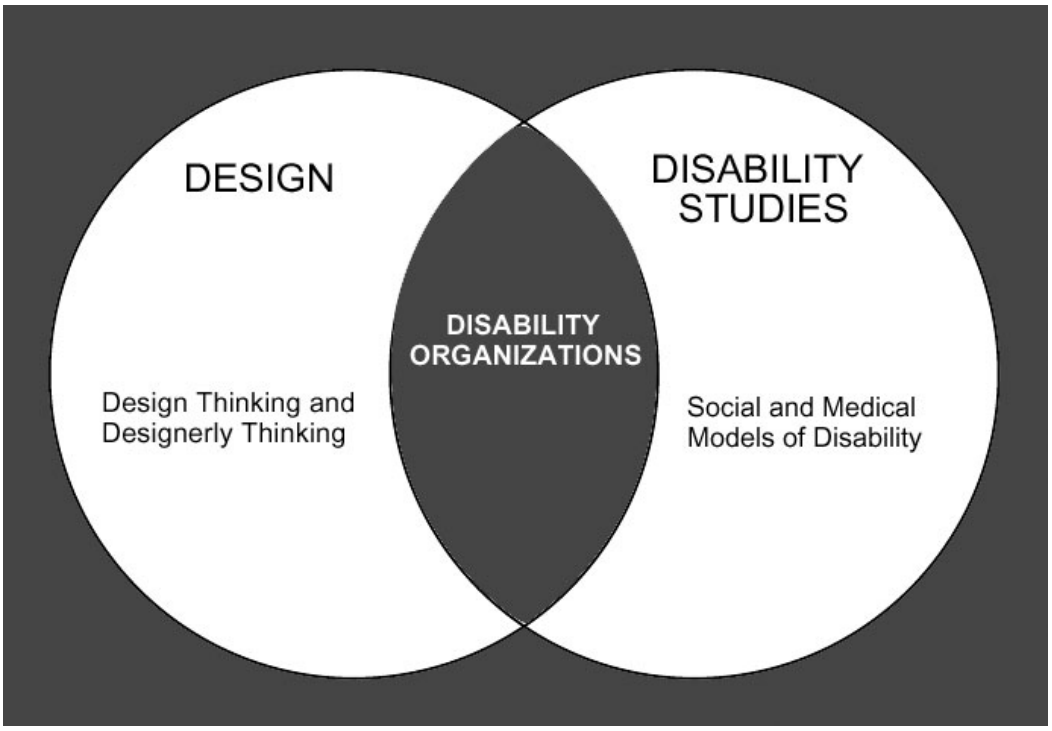

Figure 1. Venn Diagram Indicating Intersection of Design and Disability Studies.

2.1 Design Thinking

Design thinking can be put into two categories: designerly thinking and design thinking (Johansson-Sköldberg, Woodilla, & Cetinkaya, 2013). Johansson et al describe designerly thinking as the academic literature in the field of design connecting theory and practice. They define design thinking as the discourse created by other fields integrating design methods into their practice, particularly management.

They discuss five sub-areas of designerly and design thinking and the seminal works for each category:

1. Creation of artifacts, Simon, *The Sciences of the Artificial*
2. Reflexive practice, Schön, *The Reflective Practitioner*
3. Problem-solving activity, Buchanan, *Wicked Problems in Design Thinking* (1992)
4. Reasoning/making sense of things, Lawson, *How Designers Think: The Design Process Demystified* and Cross, *Design Thinking*
5. Creation of meaning (rather than artifacts), Krippendorff, *A Semantic Turn: A New Foundation for Design.*

Johansson et al also situate design thinking in the management context:

1. Design thinking according to design company, IDEO, a way to work with design and innovation, Kelley and Brown
2. Design thinking to solve a company's organizational problems, Dunne & Martin
3. Design thinking as management theory, Boland & Collopy.

To expand on the first management context, IDEO proposes a design thinking process that is composed of three overlapping areas. These are: Inspiration: the problem that needs solving; Ideation: the process of testing ideas and Implementation: the path from project into reality (Brown & Wyatt, 2010).

Inclusive Design at the IDRC follows Buchanan's discourse and considers that most design problems except for minor ones are in fact "wicked-problems" with a "fundamental indeterminacy" and can deal with subjects that are "potentially endless" where the designer positions the problems and the act of designing is different from the act of producing an actual product (Buchanan, 1992). As Jutta Treviranus, Director of the IRDC states that "inclusive designers employ edge cases or boundary cases to make sure the design can stretch to address the many dimensions of the user's requirements. It is important that the description of our user captures the perspectives we aspire to; that we can see beyond conventional stereotypes, generalizations and assumptions" (Treviranus, 2014).

2.1.1 Empathy

The idea of "empathy" emerges from the management discourse of design thinking and is a principle whereby observation of consumers and their interactions translate into insights to make better products and services (Brown, 2014). It is mentioned by Brown in conjunction with "putting people first" to gain insights by "connecting with the people we are observing at a fundamental level". Brown and Katz also state that it is the "extreme users" who will provide "new and surprising" insights "live differently, think differently and consume differently". They further explain that a collaborative relationship

between a designer and a consumer is not about "'us-versus-them,' or even 'us-on-behalf-of-them'. It is instead 'us-with-them'".

Empathy and user experience has also been explored in the field of Human Computer Interaction (HCI). Wright and McCarthy (2008) examine how empathetic understanding can be achieved through dialogue and dialogical practices.

Some in the field of design, particularly in "Socially Responsible Design", are experimenting with dialogical techniques to support inclusion (Cipolla & Bartholo, 2014). My research indicates the value of exploring dialogical techniques through a web application.

2.2 Critical Disability Studies

The World Report on Disability (World Health Organization & The World Bank, 2011) states:

> The medical model and the social model are often presented as dichotomous, but disability should be viewed neither as purely medical nor as purely social: persons with disabilities can often experience problems arising from their health condition). A balanced approach is needed, giving appropriate weight to the different aspects of disability.

The medical model of disability is characterized by a view of disability "designed by able-bodied people through a process over which disabled people have had little or no control" (Oliver, 1990). Oliver

calls this view “personal tragedy theory” and proposed it be replaced by a “much more adequate social (oppression) theory of disability” formulated by disabled people themselves to: refine disability, create a political movement, and propose services based on their needs.

Tom Shakespeare states 17 years later: “While handicap was intended to be a socialized concept, it remains dependent on impairment and disability, rather than being based on the relationship between an individual and their context” (2007). Kay Toombs (1995) describes her illness and disability not in medical terms but rather in terms of day-to-day restrictions: “…my illness is the impossibility of taking a walk around the block or of carrying a cup of coffee from the kitchen to the den.”

Vehmas and Watson (2013) explain that one of the main goals of critical disability studies is to examine socially produced differences between disabled and non-disabled people and the problems that stem from the way society defines normalcy. One of their criticisms of critical disability theory is that it doesn’t concern itself with ethical issues of day to day living and the reality of everyday life. They raise the capabilities approach of Martha Nussbaum (Garrett, 2008) as an example of a theory that has been actionable by the United Nations and other governments as the foundation for policy.

This paper will present a web application project (section 5.3) that could be actionable and facilitate dialogue to support inclusion.

2.3 A Taxonomy for Dignity

Nora Jacobson (Jacobson, 2009) took a grounded approach to investigate a taxonomy for the discussion of dignity. The research indicated that there are two forms of dignity:

1. Human dignity which is the “abstract, universal quality of value that belongs to every being simply by being human” and is considered inherent
2. Social dignity which “is generated in the interactions between and among individuals, collectives, and societies” and since socially produced can be “measured, violated or promoted”.

The research continues to state that social dignity can be divided into two types:

1. *Dignity-of-self* which is the quality of self-respect/self-worth and can be identified with characteristics of confidence and integrity
2. *Dignity-in-relation* refers to ways in which respect and worth are conveyed through individual and collective behaviour.

In addition, “every human interaction has the potential to be a dignity encounter” that could be either a *dignity violation* or a *dignity promotion*.

In this study I refer to social dignity. This is a very interesting concept especially in that some disability researchers have called for practices that enhance “interactional inclusion” (Church, Frazee, Panitch, Luciani, & Bowman, 2007). In fact, such practices would be considered a form of *dignity promotion* as defined in Jacobson’s research.

3 Methods

My research initially proposed to investigate a sustainable business model for disability organizations whereby these organizations act as service providers of inclusive design and testing services to businesses that need this expertise. Two pilot interviews were conducted in May 2014 to explore potential interest in the project.

3.1 A Grounded Approach

My introduction into qualitative research included Creswell's text *Qualitative inquiry & research design: Choosing among five approaches* (2013). Grounded Theory seemed relevant to my research, given that I wished to generate a model from insights provided from outside the current literature. I wanted to generate a model from the stories, perspectives, and passions shared by those who are currently working with disability organizations in a variety of ways. Grounded theory is also becoming "increasingly popular in interaction design to answer specific questions and design concerns" (Rogers, Sharp, & Preece, 2011).

Grounded theory has as its basic premise the generation of a theory or understanding through systematically analyzing the research data. Different refinements on methods have developed as to how to carry

out the procedure of grounded theory (Bong, 2002). For instance, Charmaz (2003), a noted constructivist, points out that a grounded researcher must study emerging data carefully and pay special attention to a participant's use of language. Examination of language is also a hallmark of critical disability studies.

I am following the procedures of Juliet Corbin and Anselm Strauss (2015). Corbin states, "I agree with the constructivist viewpoint that concepts and theories are constructed by researchers out of stories that are constructed by research participants who are trying to explain and make sense out of their experiences and lives, both to the researcher and themselves. Out of these multiple constructions, analysts construct something called knowledge."

Corbin talks about the importance of sensitivity, self-reflection, questioning, constant comparison, diagramming, memo writing and common sense.

Two features that Corbin and Strauss (2015, p. 14) attribute as unique to grounded theory and occur across all schools of grounded theory discourse are:

1. The concepts constructed are derived from the data and are not chosen prior to the research.

2. Research analysis and data collection are happening at the same time and guide further data collection.

3.2 Participants

Twelve participants were interviewed for this study. Each was already familiar with accessibility and disability issues and they possessed diverse backgrounds covering a wide range of perspectives (See Appendix B). Semi-structured interviews were chosen due to the flexibility and customization of questions depending on the individual's expertise and flow of the interview. Half of the interviews (6) were conducted over the telephone, five in person and one over Skype.

The participants' expertise covered view points from the following fields:

1. Disability organizations (as employees or clients)
2. Design industry
3. Disability employment
4. Business
5. Accessibility expertise (renowned in field)
6. Education.

In terms of gender, five of the participants were female and seven were male. Only two participants were in the age bracket 26-35 years, with most being middle aged as shown in Figure 2.

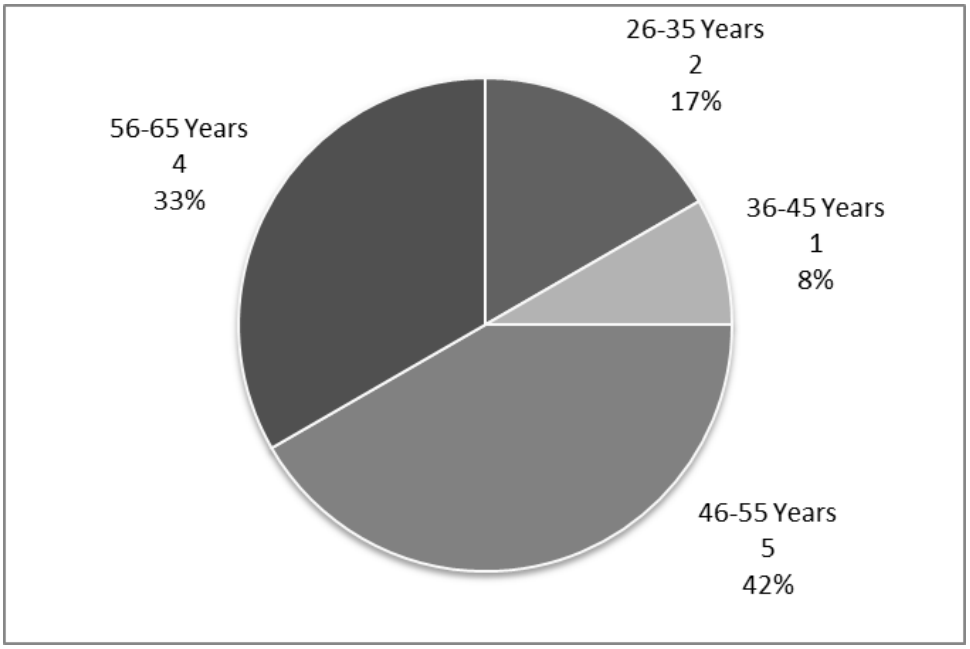

Figure 2. Pie Chart Indicating Distribution of Age of Participants.

Most participants (10) were located in Ontario, Canada with one in Western Canada and one in the United States. In terms of impairments or abilities, there was a wide range from mild to severe and some participants had more than one. One participant had no impairments. One participant created a new category for extraordinary hearing because he used echolocation. See Figure 3 for the breakdown.

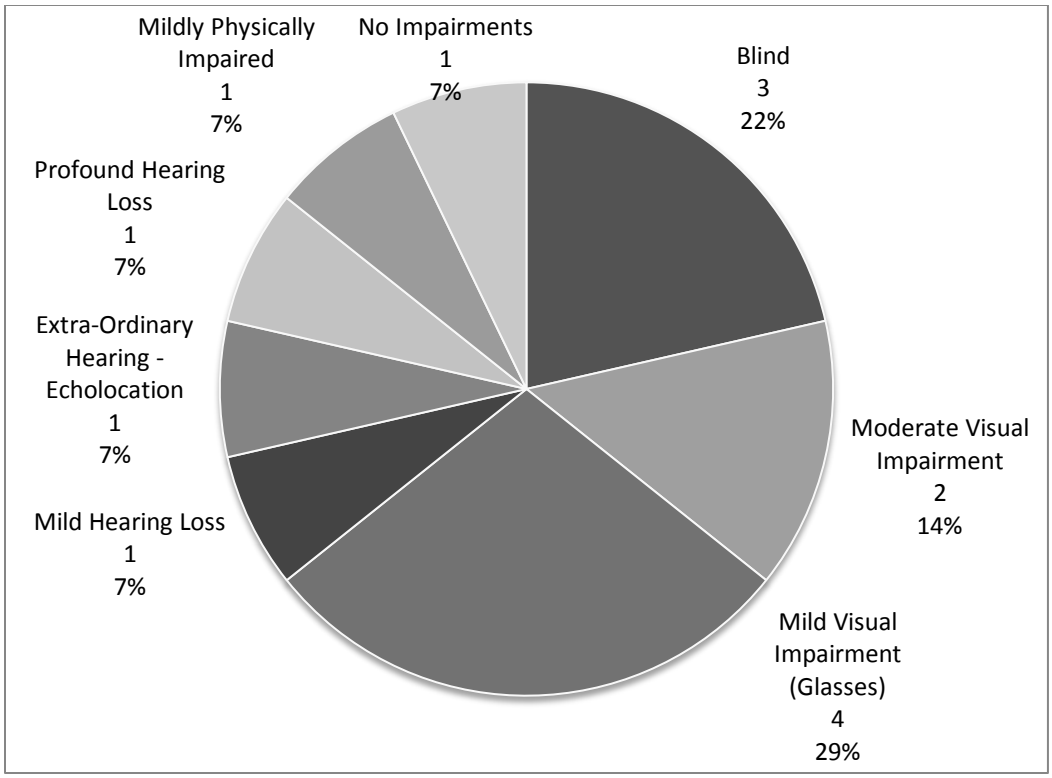

Figure 3. Pie Chart Indicating Impairment or Abilities of Participants.

One last thing to note is the participants' existing relationship with a disability organization. One had no affiliation, while the majority either were clients or had a business to business relationship as indicated in Figure 4.

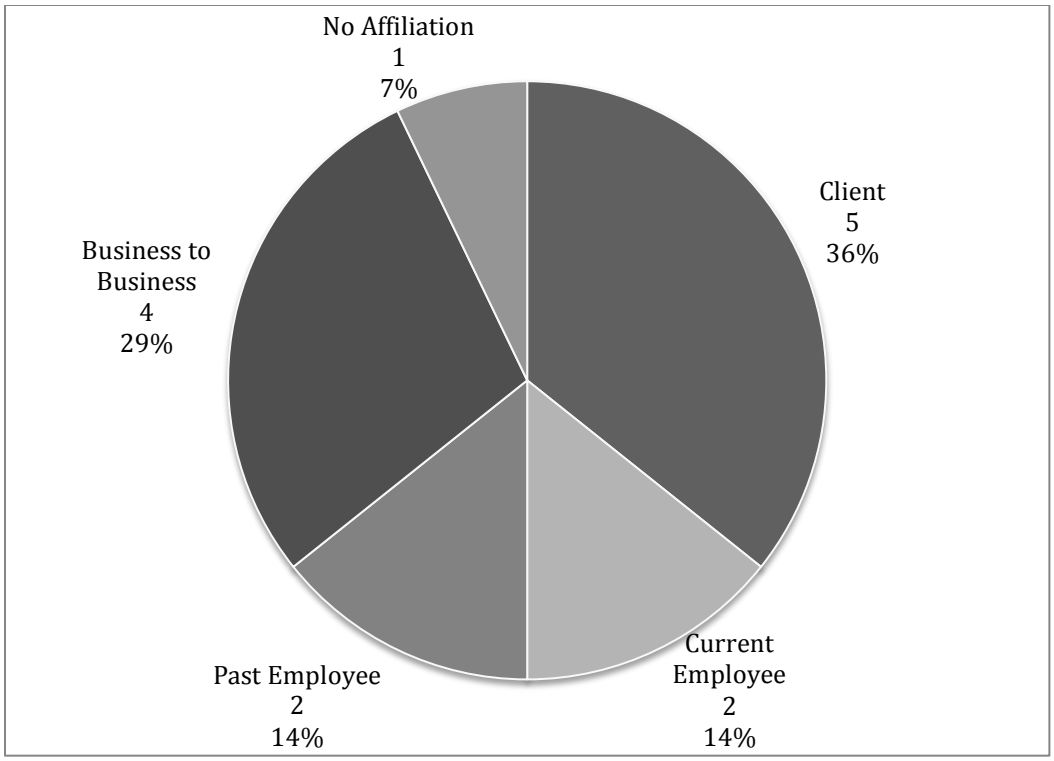

Figure 4. Pie Chart Indicating Participants' Relationship to a Disability Organization.

Corbin and Straus describe theoretical sampling, a hallmark of grounded theory, as concepts are sampled instead of people and the researcher follows important ideas or themes brought up in the interview, regardless of whether or not the questions are different from the previous interview. Also, the researcher may bring up previous concepts at the end of the interview if they were not covered (Corbin & Strauss, 2015, p. 139). True theoretical sampling was not achieved in this study as this is only possible if the concepts and properties of the data are thoroughly examined between participants.

3.3 Procedures

A total of twelve (12) interviews were conducted from September 24 – November 13, 2014.

3.3.1 Recruitment

Participants were recruited formally via an Invitation/Informed Consent Form (Appendix C – Invitation Informed Consent), and became known to me through accessibility conferences such as Designing Enabling Economies and Policies (2014), Accessibility Camp (2014) , Web Accessibility Conference (Registered Graphic Designers RGD, 2014), or referral or contact as stated in the approved Research Ethics Board application. Each eventual-participant had recent in-person or phone contact. Two participants, who were referred by colleagues, wished to speak with me via telephone prior to participating. Approximately three invitations were sent out for every one participant in the study.

Initial plan was to interview 17 participants, but recruitment was stopped after 12 participants were interviewed in order to review and absorb what had already been collected and do further comparisons.

3.3.2 Data Collection

Data were collected through private semi structured interviews, audio recording, and note-taking. One participant did not consent to audio

recording and only note-taking occurred. Six interviews were done over the telephone, five were done in-person and one was conducted over Skype.

3.4 Instruments

3.4.1 Interview Protocol

Semi-structured one hour interviews were conducted using objective, reflective, interpretive and decisional questions (Stanfield & The Institute for Cultural Affairs, 2000) that explored inclusive design and involvement of disability organizations. (Appendix D – Interview Guide and Appendix E – Demographic Questions).

Theoretical sampling, a hallmark of grounded theory, means concepts are sampled instead of people. The researcher follows important analytical ideas brought up in the interview, regardless of whether or not the questions are different from the previous interview; also, the researcher may bring up previous concepts at the end of the interview if they were not covered (Corbin & Strauss, 2015, p. 139).

3.4.2 Data Recording

Interviews were audio-recorded and transcribed and analyzed using Transana (University of Wisconsin-Madison Center for Education Research, 2014)

Data were stored on a password-protected computer, with a back-up on a locked hard drive.

3.5 Data Analysis

Recording and analysis of the data took several forms such as coding, memoing, journaling and web application framing which are described below.

3.5.1 Coding

In grounded theory, coding means “denoting concepts to stand for meaning” (Corbin & Straus, p. 57). Coding is done as one form of constant comparison analysis. The process is always changing and the codes are changing until theoretical integration (Birks & Mills, 2011). Coding can help researchers see familiar information in a new way, and distance themselves from their and their participants’ assumptions, which can potentially lead researchers in an unintended direction (Thornberg & Charmaz, 2014).

The coding of the interviews was done in Transana (University of Wisconsin-Madison Center for Education Research, 2014) where the main analytic unit for coding is termed a clip. A clip is the portion of the interview or raw data selected for analysis. Clips can have descriptive titles that summarize their content. Clips have the finest

granularity of all the analytic units in Transana. Other analytic units in order of increasingly coarser granularity are clip titles, sub-collections, collections, keywords, and keyword groups.

Figure 5 denotes a sample clip and its relationship to the other analytic units. In this figure, the finest granularity, the clip in the right hand column was assigned the clip title “Duty to Accommodate under the Human Rights Code” to denote a summary of the main idea of the clip. The clip title was assigned to a sub-collection called “Employment” that is within a collection called “Barriers” of medium granularity. If no suitable collection or sub-collection existed at the time of assignment, a new collection would have been created. In addition, keywords were assigned to the clip. In this case the keyword group is “Ecosystems”, the coarsest granularity, and the keywords are “Day-to-Day Living”, “Industry & Business”, and “Legislation, Regulation & Government”. If no suitable keywords existed at the time of assignments, new keywords would have been created. This constant comparison of data while coding is a hallmark of grounded theory.

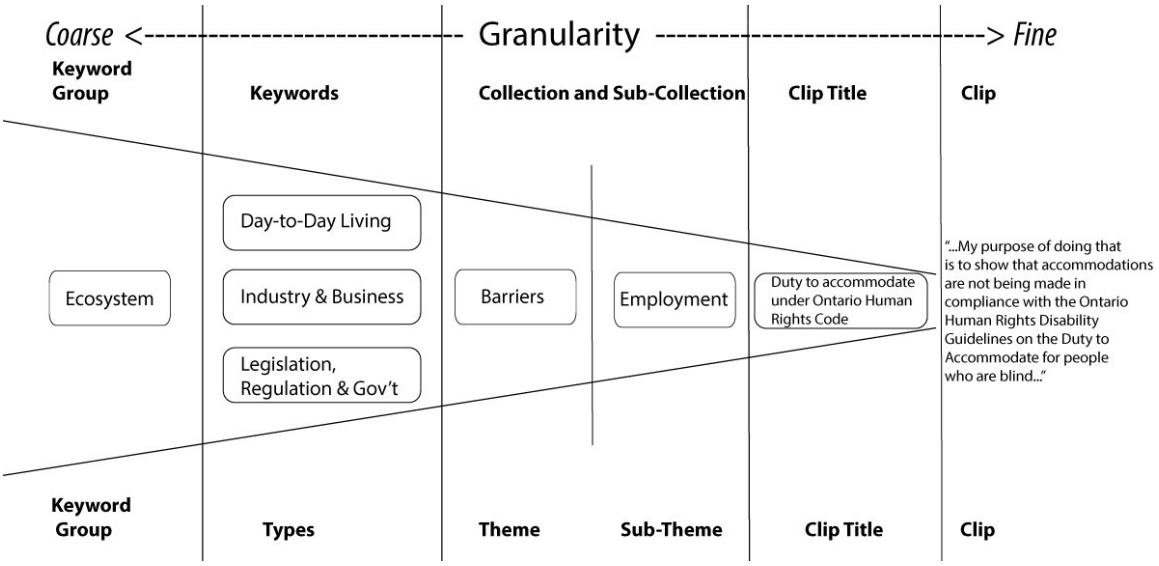

Figure 5. Granularity of Analytic Units Used During Coding.

The length of a selected clip is based on a subjective evaluation of the participants' thoughts, interactions or information with respect to disability organizations and design. Depending on what the participant was saying, I capture d a sentence, a paragraph, or a group of paragraphs. During this process, I relied on previous professional experience in information architecture to allocate placement in the system and used a disjoint free-sort to allocate a clip to one thematic collection (Coxon, 1999). Note that multiple keywords could be assigned to a clip if those keywords held relevance within the clip.

In keeping with the principles of Corbin and Straus, the coding of the clip title, collections and sub-collections was done via open coding to identify concepts. The creation of keywords was through a process called in vivo coding which documents the actual words the research

participants used. I stopped short of axial coding (developing concepts in terms of their properties and dimensions) due to time constraints.

3.5.2 Memoing

Corbin & Straus (2015, p. 118) indicate that memos allow researchers to keep track of their progress or lack thereof in the analysis. The purpose of memoing is to further thinking about the data. Memos were made during the coding of the interviews using the note-taking function in Transana. Some examples of memos are provided in Table 1 below:

Table 1. *Example of Memos Made During Grounded Analysis*

Time Stamp	**Memo**
11/8/2014 9:31:48 pm	Accessibility is a thing; but inclusive is an approach
11/17/2014 5:59:33 pm	Added another Ecosystem - Day to Day Living as the participant talks about how integral ICT is to every waking minute.

In addition, memos went up on the wall on coloured sticky notes. The project branched tactilely out as seen in Figure 6 which allowed for casual reflection on the project.

Figure 6. Photo of Memos Arranged on the Wall.

3.5.3 Research Journal

Corbin & Straus (2015, p. 119) recommend a research journal to enable self-reflection while doing research in order that the researcher can better recognize his biases and assumptions. Evernote is an application available on phone, computer or tablet that allows notes be taken anywhere and viewed on different devices with a date-tracking and search feature (Samuel, 2013). I used Evernote as a research journal for field notes, random ideas, thoughts, meeting notes, conference activities, and potential literature to review or investigate.

Example of some notes from Evernote:

Tuesday Feb 10
Current design thinking models call for empathy - but I would go further and say that inclusive design thinking requires the consideration of dignity and dignity needs to be at the core.

Feb 11 - trying to combine innovation/creativity at the same time - respecting people with disabilities; — disability studies does not support simulations - tension between the ideas of design and empathy — and no simulations.

3.5.4 Research Website

To enable me to document my journey and share it succinctly with advisors and interested colleagues, I set up a password-protected website using Drupal (2014). The site gave visitors the ability to comment on any posted items. Navigational buttons or categories on the site continued to grow and gave me a snapshot of how the research was evolving. Navigational categories on the site are:

- Overview- Providing background and succinct summary of the research purpose
- Learning Plan-This page covered research questions, assumptions, biases, body of research, key word assignment, and possible publication venues
- Framework – The phases of research for the project
- Interviews – Quotes from participants, key word and collection assignments. All information was completely anonymous
- Literature – Bodies of thought and literature
- Timeline-Key dates of significance

- Model – A diagram showing a visual representation of the merging of concepts uncovered
- App - The web application
- Glossary of Terms.

If a visitor did not sign into the site with an ID and password, he received an “access denied” message. This page of the site, retrieved April 8, 2015, is provided in Figure 7.

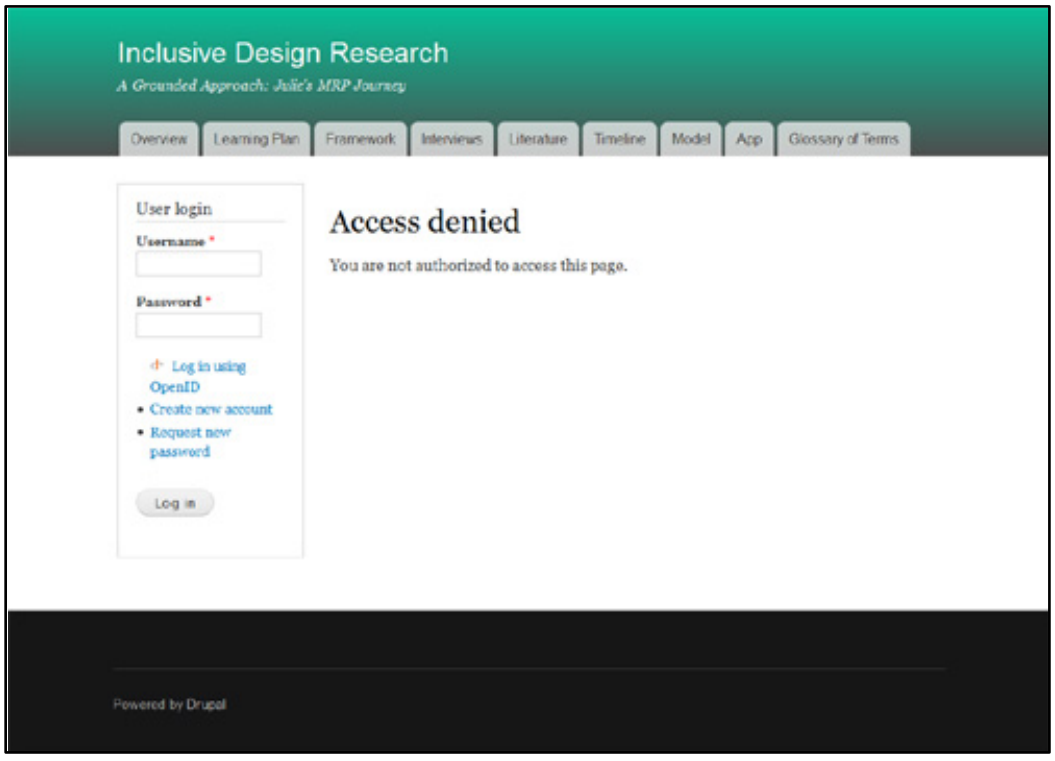

Figure 7. Screenshot of Research Website.

3.5.5 Web Application Framing

Creating a web application framework was a tangible way to express the findings I was uncovering. Similar to diagramming, mapping out a web app was a way for me to organize my thoughts and allow practical execution of the emerging theories. As Tom Kelley (2001) states, “A good prototype is worth a thousand pictures.” Usually one thinks of a web app as an end product, but in this study, mapping out a web app framework was a way to solidify concepts and a step in the data analysis and research process. The application is discussed in more detail in section 5.3.

3.6 Summary and Reflection

My research intent was to design a model based on insights from a diverse group of participants. I chose to follow the Corbin & Strauss school of thought because in my practical experience of developing websites, I would draw from both quantitative data (web statistics and web surveys) and qualitative methods (focus groups and usability testing) to make decisions. The grounded approach satisfied my desire for a structured and methodical way to analyze open-ended interview questions that would change from interview to interview. The study drove me to seek out the answers to questions I had in what to me is a new field of study--critical disability studies.

If I were to start again with a grounded study, I would take more time between each participant to analyze and reflect upon their interviews. I would continue to use a software program for the coding and organization of interview data in addition to seeking out other researchers who were also conducting grounded theory studies. I found it helpful to construct something practical (in my case a web application framework) to put the emerging themes and theories into action.

If I had not used a grounded approach, an ethnographic study of participants from one disability organization may have yielded more focused answers toward my initial aim of creating a business model. As it was, the grounded analysis grew increasingly broader and deeper in scope, which made it difficult to remain with the initial research question.

In addition, this study does not utilize all the techniques of grounded theory and adds additional elements such as a research website and a web app that are not associated with grounded theory, but were helpful in synthesizing ideas. Although I incorporated the ideas and thoughts of past participants into questions for future participants, I had not fully coded and analyzed between each interview as full-grounded theory demands.

4 Findings

The findings were analyzed using different coding methods at different levels of granularity. As indicated in Figure 7, section 3.5.1, coarser granularity or level of detail is represented via keyword groups and keywords, finer granularity is via collections and sub-collections of themes, and the finest granularity is via clip titles and clips (extractions from the raw data). As I continued to code and constantly compared clips, the collections of themes morphed and grew.

Approximately nine hours of recorded interview time was reviewed and coded. Some findings are presented in terms of amount of time participants spent discussing keyword groupings and themes. Analyzing the time spent gave me as a researcher a better idea of what we really talked about over nine hours. It also gives greater context to individual clips and quotes. In addition, time spent gave structure to the presentation of findings where the largest keyword groups are discussed first, followed by smaller. It doesn't mean the smaller groups are less important; rather it indicates that in the context of the interviews and participants, certain themes and keyword groups were discussed more than others.

4.1 Accessibility Keyword Group

“Accessibility” was the largest keyword group in the research and was created because of the number of ways accessibility was described or referred to by participants. After all the interviews were coded there were over 100 different words or phrases that referred to accessibility. (See Appendix F – Words Related to Accessibility).

For example, one keyword phrase was “so-called experts” – to describe people who work in the field of accessibility, but are not knowledgeable about disabilities, assistive technology, legislation or other aspects of the field. The keyword “so-called experts” was assigned to 13 different clips spanning six different themes. One example of this phrase being used in the research is:

- “You have to be careful with saying our disability organization has expertise in-house. We still need to work in collaboration with those people who may have the *‘so-called technical expertise’* because we’re still the end users.” ~Participant

Another keyword, “Mainstream”, was used to refer to traditionally assistive technologies that were becoming available and usable by everyone; also it was said that disability is becoming a “mainstream” experience. “Mainstream” was assigned to 15 different clips spanning across 7 themes. One participant used the term in this way:

- “Let’s stop thinking about people with disabilities as the exception. Let’s start thinking of them as the new normal, or a major part of the ‘*mainstream’*.”

This keyword group indicates that even though the participants were familiar with disability, they were very diverse when it came to expressing and interpreting accessibility.

4.2 Ecosystem Keyword Group

One keyword group, called “Ecosystem” indicates the idea of interconnected relationships between devices, people and environments. An ecosystem is more commonly defined in terms of the physical environment where connected relationships between organisms create a sustainable system. A digital ecosystem is a “metaphor of an ecosystem, where components of a digital economy function together as a sustainable system” (Yamakami, 2010). Similarly, the ecosystem metaphor is used in this study to categorize and discover the inter-connected worlds to which the participants are referring. Hinman (2012) describes a digital ecosystem as the interactions between the pieces, services, systems, and processes of a digital system that include digital devices, people that interact with them, and the business processes and technology environments that

support them. Categorizing clips as to ecosystem reflects my background as a web designer and comfort in the digital space.

As explained in section 3.5.1, I created the Ecosystem keyword group to represent big picture ideas and assigned different Ecosystem keywords to a clip based on the topic(s) of conversation. For example, if the participant was talking about a disability organization, the clip was assigned and coded with the Disability Organizations & Communities keyword. If the participant talked about training within a disability organization, the clip was assigned two Ecosystem keywords, 1- Disability Organizations & Communities and 2-Training & Education. . One clip could have many Ecosystem keyword assignments. The Ecosystem keywords evolved and changed throughout the process as I coded more and more clips. For simplicity they are referred to simply as “ecosystems”. Sometimes it was necessary to go back and assign a new Ecosystem keyword to an earlier clip based on a later interview. Eleven ecosystems indicate the broad range of conversation and the diversity, expertise and broad knowledge base that the participants possessed.

Table 2 shows a summary of the keyword group Ecosystem, the total number of clips assigned, and total time of the clips assigned.

Table 2. *Ecosystems, Meanings, and Attributes*

Ecosystem Keywords	Meaning Ascribed During Coding	Number of Clips Assigned	Total Time (H:M:S)
Disability Organizations & Communities	Organizations providing services for persons with disabilities and also formal or informal communities participants identified with	63	1:27:17
Industry & Business	Commercial or for-profit enterprise	59	1:20:03
Training & Education	Training required or offered via college, university or another method	44	1:09:01
User Experience & Design	A person's experience with items or systems and the design process	39	0:59:38
Day-to-Day Living	Daily life and the activities of daily living	39	0:48:34
Legislation, Regulation & Governments	Laws, check-lists, formal systems of enforcement	36	0:41:47
Research & Funding	Disability studies, design and market research and funding mechanisms	12	0:20:23
Software & Hardware Systems	The products and processes involved with computer systems	11	0:15:14
Testing & Development	Testing and developing products and services	12	0:13:31
Content Creators	People who create the content for websites and products. They use words and descriptions. They might not have technical skill but have expertise in the subject matter	10	0:13:16
Project Management	The logistics of taking a project from start to completion	8	0:10:10

A visual representation of Table 2 is shown indicating the number of clips assigned an Ecosystem keyword (Figure 8) and cumulative clip

times in minutes per ecosystem over 11 recorded interviews (Figure 9). A total of 333 clips were assigned with one clip being able to have one to many keyword assignments. Total clip time assigned totaled 455 minutes or 7.5 hours.

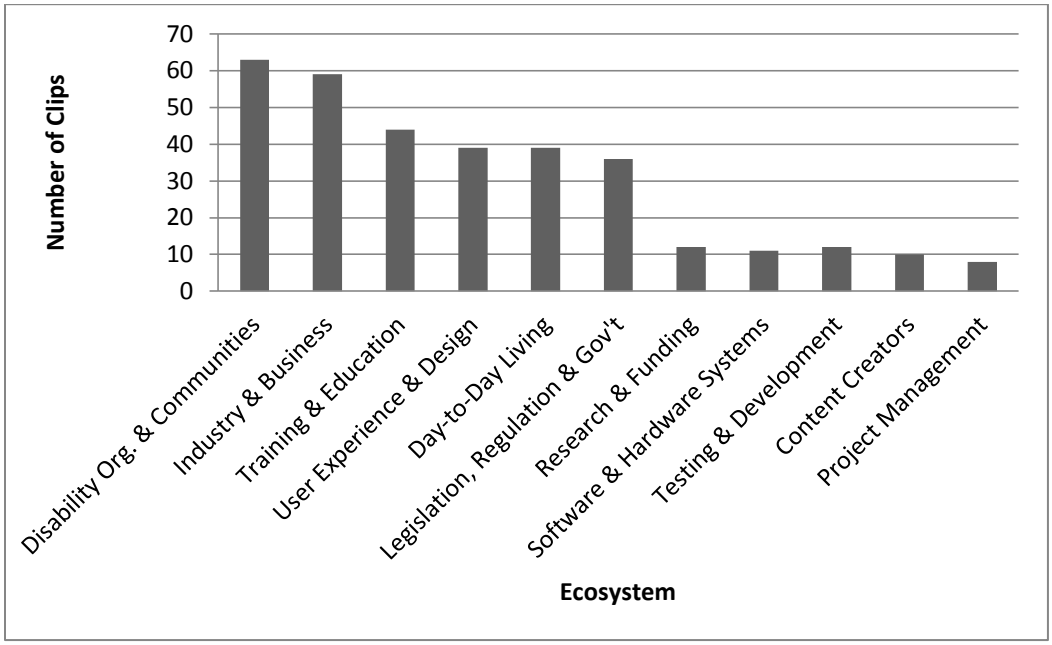

Figure 8. Number of Clips Assigned to each Ecosystem over 11 Recorded Interviews.

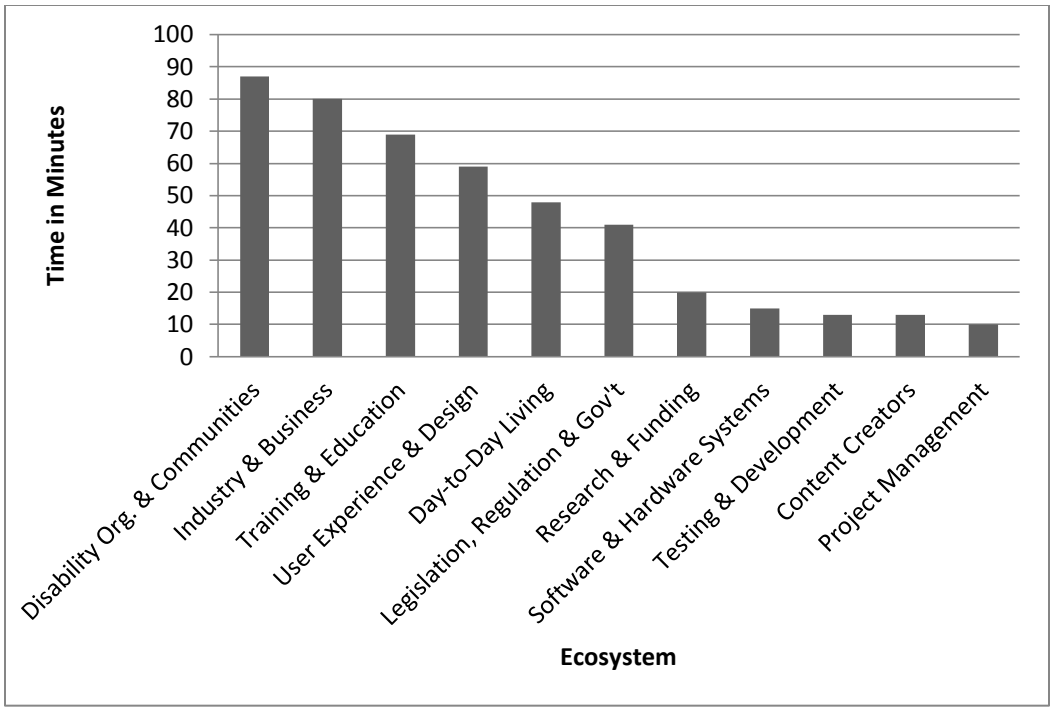

Figure 9. Cumulative Clip times per Ecosystem over 11 Interviews.

4.3 Ecosystem Contents

In the following section, representative comments are provided for each ecosystem. The participants, other than having knowledge of disability organizations and disability issues, were vastly different from one another. They came from different walks of life, with different jobs, roles, and from different industries. The different ecosystems indicate the participants did not necessarily have shared life patterns or beliefs. Many comments speak directly to violation of social dignity as described in section 2.3, and other comments represent dignity promotion.

4.3.1 Disability Organizations and Communities

This ecosystem encompasses both disability organizations and information communities because some of the participants spoke of their community as an informal collective of people sharing the same impairment.

Participants spoke of participating in focus groups hosted by disability organizations and not being paid with anything other than pizza. Disability organizations need to consider the dignity of their own constituents, even in something as simple as paying participants for joining a focus group.

With regard to service cuts, one participant expressed his frustration:

- “They closed all their regional offices to save money and so what about online services? Where are the online services? Oh well we're working on it. Yeah, well you know what? It's 2014 and you can't just keep working on the online services.”

One participant spoke of approaching a disability organization for guidance on a product he was developing. The organization told him his product would never work, they didn’t have funding and they couldn’t help him. He felt disheartened by the response especially when his companion said to him afterwards, “What the h---! You’ve been dealing with these people all your life?”

In terms of developing design services, one participant who had previously worked with a large disability organization was confident that if an organization wanted to develop accessibility consultancy expertise, it could. However another participant was concerned that large disability organizations were selling accessibility consulting services to businesses at below-market prices. He said, “Since they are funded by donors they can do this, but they are undercutting small businesses run by people with disabilities in the process.” Another participant also pointed out the practice of disability organizations not charging a fair market rate for accessibility expertise to businesses and called it “unsustainable”.

For disability organizations to practice dignity promotion with design services participants’ comments indicate that disability organizations need to charge a fair market rate for services, pay participants a fair wage for their time, keep up with technology, and support the new and innovative ideas of their constituents.

4.3.2 Industry and Business

This was the second largest ecosystem. Themes ranged from considering whether a disability organization should become more business-like to businesses competing with disability organizations. Also mentioned were quality issues with service delivery. This

ecosystem also covered software vendors supplying accessible software and business collaboration amongst different disability organizations.

One participant spoke of starting a new job:

- “You sink or swim. Accommodation is not just about physical access or supplying the right computer program. It is also about integrating the person’s social support so that you don’t have to bother people. You need to have somebody, a peer, you can go to if you can’t find the website or if the mouse doesn’t work or if something goes wrong.”

Regarding small businesses run by disabled people, one participant felt it was impossible to compete with a large disability organization for contracts even though he felt his company provided a better service:

- “Unfortunately when it comes to those [government] contracts, there is a bid process, and in [the accessibility] industry we are up against competition such as [large disability organizations]. We just can't compete with the [them], even though they really don't know what they are doing.” ~Participant.

Disability organizations can engage in dignity promotion by supporting positive social interactions for people with disabilities in

the workplace. Also disability organizations need to look at policies that prevent direct competition against small businesses owned by people with disabilities.

4.3.3 Training and Education

There was a great deal of discussion about technical training for and by people with disabilities, and education needed to break down myths and assumptions. There was also discussion about informal education communities as well as formal education. Many participants spoke of the need for people with disabilities to learn technical skills that can lead to jobs.

One participant, an educator, expressed that even educators carry assumptions about people with disabilities, and in this case was particularly impressed by her student's ability to self-advocate:

- "I had grave concerns about a senior student who was legally blind taking a senior art course when I was supposed to be preparing her for college or university. I had some preconceived notions and this girl's work was amazing."
  ~Participant

Another participant spoke of the need for social integration in the school system in order that people with disabilities don't grow up feeling excluded:

- “I would like to see more access not just for adults with the AODA, but for schools too. There need to be ways to get kids to interact with sighted children and others and learn social skills. [Otherwise]They grow up and nobody wants to mix with them. As teenagers, they get isolated because they can go for a beer; they don't drive; other sighted kids are not going to include them in their fun; they are not going to do things that sighted kids do such as participating in sports; so they would have to participate in disability types of sports. They don't get full social inclusion.”

Another participant talked about the benefits of a community of practice at her place of employment as an informal learning opportunity to raise awareness and technical skills needed to make technology accessible.

Dignity promotion in this ecosystem would revolve around facilitating technical skills training as well as a social integration component in order to enable integration of people with disabilities smoothly into the workforce and society.

4.3.4 User Experience and Design

The challenge of designing for accessibility and usability at the same time was a theme, as was design process.

One participant spoke of their design process that unfortunately does not involve people with disabilities even though the company aims to produce accessible software:

- “We don't do a lot of participatory or co-design. We tend to, based on our internal knowledge, come up with the best solutions we can come up with and then tweak based on our feedback. We'll use our accessibility interest group to help us with our initial requirements”

Another participant talked about inclusive/universal design, but pointed out that there will be a need for specialized design for some items because individual needs can be very specific:

- “Design is very subjective it depends what you are designing for. If it is just design and disability it is very broad so I would like to see it narrower. What are you designing? Something physical? Online? Something for people to use? It depends what it is. Design for me and I use the term universal design -- that is the big buzz word. I would think of something that is benefiting everybody at the same time. But there are some things that would have to be specialized for blind people. Not everybody is going to want a talking clock.”

Dignity promotion in this ecosystem would be connected to promoting the lived experience of the constituents of disability organizations to provide design insights and skills to businesses. Care would need to be taken that constituents are fairly compensated for their participation. Also, the nuances between inclusive design and specialized design need to be addressed.

4.3.5 Day-to-Day Living

This ecosystem encompasses the things done on a day-to-day basis such as working, banking, shopping, eating, conversing, and meeting people. Even though the planned interview protocol focused on disability organizations and design, the conversations turned to everyday problems and the disruption caused by disability on a daily basis, while engaged in the activities of daily living. For instance, one participant spoke of travelling with his guide dog. He needs specific information about where to go otherwise his safety may be impacted:

- ”It is one thing to find a dog friendly hotel and then walk out the front door and kind of look around and say, okay, it looks like we could take him over there. But for someone who doesn't have any vision, you are not just going to start wandering in a neighbourhood that you are not familiar with.” ~Participant

The activities of daily living mean all people are busy. One participant recognized this and had an idea for dignity promotion out in the greater community:

- "Nobody is going to set up a separate time to learn anything about disability. So it has to be included into what they are doing e.g. the coffee hour at the church. It's got to be community education – community-based education."

Any steps forward in the other ecosystems that enhance dignity in interactions will have a positive and beneficial impact on day-to-day living.

4.3.6 Legislation, Regulation, and Governments

This category was originally called legislation and regulation, but government was added because of the government programs and departments directly involved with accessibility legislation. Within this category are conversations regarding standards in the built environment as well as in the digital environment. The category also covers checklists, Web Content Accessibility Guidelines and any form of standardization, or government programming that formalizes accessibility in some way.

Legislation was viewed by one participant as effecting positive change and offering dignity promotion:

- “Personally I feel that legislation does make a difference being in the industry that I'm in. There's a lot of very active thought around legislation to ensure that we have equal opportunities and education to learn."

Another participant pointed out that legislation requires enforcement by the government or else all the potential dignity promoted through the legislation is lost:

- “You are not going to get change unless people get awareness and the awareness has to come from the government. It's got to come from the top. It's got to be something they believe in. They have got to support it and if they don't want to support it, they are going to undermine it. Getting people to go and demonstrate is not going to solve the problem.”

Another participant pointed out that standards need to be in place to have accessibility because people say, ‘Where are the standards? What do you have to do?’ Standards can assist with dignity promotion.

4.3.7 Research and Funding

An ecosystem emerged around the funding of accessibility and further research. Themes emerged around the need for more research, the

set-up of research clusters and suspicion of private funders. Census surveys, collaboration, government grants, needs assessments and evaluations came under this category.

One participant from within the software industry talked about internal company policy toward diversity in research and thus dignity promotion:

- “As far as internal practices or culture within my area of the organization which is within engineering or research and development, we are organized in cross functional teams so that each team has a variety of skill sets that are working together to a common solution that you have a lot of cross-pollination of knowledge and a lot of geometrics to come to solutions. You get a wide variety of perspectives towards whatever solution you're working on.”

Another participant felt it was important to know the intent of the research to decide if it is manipulation for material gain:

- “One thing I'm leery about if it's a private company-- why are they funding [this grant]? Is it because they're a Kleenex company and they're cutting down trees so they want to do a good PR campaign? Is there an ulterior motive behind why they're funding? And then part of me says with increasing

demands on school budgets, there's nothing inside a school budget for (inclusive design) really."

4.3.8 Software and Hardware Systems

This ecosystem covered how hardware and software systems can aid in accessibility and independent living.

Accessibility can be built into the operating system, but a software developer can inadvertently break the accessibility and thus produce a loss of dignity:

- "Apple says that the more you can leave your stuff set to the standard, it'll just be accessible to voice-over because that's what voice-over is expecting. Accessibility starts to get bad, the more you start to fiddle with the basic functions to make your app look groovy and cool and do whatever." ~Participant

For this participant, technology has brought simplicity and independence, which is dignity promotion:

- "iPhones and iPads can become kind of a 21st century independent living appliance because traditionally you went out and bought a light detector, that's one piece of hardware, a colour identifier, that's another piece of hardware, a GPS, that's another piece, and so on to enable independent living; now you can have that entire mess all in your iPhone."

4.3.9 Testing and Development

The interesting thing about this ecosystem is that the interviews were about finding out if disability organizations could do co-designing and testing. Themes of certification, teamwork and communities of practice arose in this ecosystem.

One participant spoke of the need not to focus on only one type of assistive technology equipment which is promoting dignity for everyone:

- “I mean you could make a website that worked beautifully with a screen reader and still look really weird on a screen and if you're trying to be part of the real world, you can't have something sitting up there that when someone logs on and looks at it, their one and only reaction is what the h--- happened here? Click, next thing.”

One participant spoke of the need for collaboration and teamwork both interdisciplinary and people of all abilities because everyone has expertise in certain areas. Teamwork is dignity promotion.

One participant pointed out that since accessibility is an emerging industry, certification can help identify knowledge, trust and promote dignity.

4.3.10 Content Creators

This ecosystem referred to the people who create the content for websites, products and services. Their tools are words and descriptions. They might not have technical skill, but have expertise in the subject matter. The clips coded in this ecosystem talked about WordPress, research panels, captioning, and social media. With these tools, disabled people can now create their own content for mass distribution. This trend will only continue. Regarding social media one participant said:

- "The cool thing now is you've got WordPress, so you just find out which one of the themes has been deemed accessible. Other people have done all the work. You install the theme and just start going…If you get the right Twitter following or the people are following you on LinkedIn or anything and you send one of these kind of universal messages out, it gets distributed exponentially and if it's something that's really cool and people are interested in, you could end up having more people to draw on than you'd know what to do with. It doesn't have anything to do with any traditional agency or organization."

Content creators can either promote dignity or violate dignity, depending on what they create.

4.3.11 Project Management

This theme concerns how accessibility can be left out of projects due to competing demands, and how accessibility is seen as a costly add-on to a project rather than being embedded at the project onset.

One participant offered words of wisdom and thoughts pertaining to dignity promotion:

- “Accessibility is not an addition to the process; accessibility must become the process itself. So it can't be seen as an afterthought, it can't be seen as something that costs extra. It has to just become a part of the process like everything else and to do that it requires a cultural change.”

4.4 Themes

Thematic collections (themes) are more specific with finer granularity than ecosystems and only one clip was assigned to each theme. Themes were established through open coding as detailed in section 3.5.1. All twelve themes created are listed in the table below. The themes are listed in descending order by number of clips coded per theme. The purpose of the table is to provide greater context to individual clips and quotes extracted from approximately 9 hours of total interview time.

Table 3. *Themes and Sub-Categories Derived from the Interviews*

Theme Name	General Topics or Sub-Themes (if Applicable)	Number of Clips Coded	Total Time (H:M:S)
Disability Organization	Politics, fundraising, partnering, spending, advocacy, service delivery	36	0:39:36
Barriers	Employment, lived experience, media and volunteerism expected.	32	0:41:28
Training & Rehabilitation	Certification, community of practice and technical skill.	26	0:39:00
Organizational Process	Implementation and process.	24	0:25:17
Design	Physical space, technological progress, visual design.	21	0:28:38
Disability	Business case, legislation.	17	0:22:46
Independent Living	Skill development, technological mastery.	12	0:16:32
New Ideas	Hubs, training institutes, design centres.	11	0:17:38
People With No Clue	Lack of awareness.	8	0:09:39
Testing	Regulation.	7	0:11:10
Vendors	Sellers of products or services.	5	0:10:07
Complex IT Set-up	Specialized equipment.	4	0:06:37

The total number of clips coded was 203 with cumulative time of 4.4 hours. “Disability Organizations” was the largest theme with 36 coded

clips for a total of 39 minutes of time. Second was “Barriers” with 32 coded clips for a total of 41 minutes of time.

Figure 10 provides a visual representation of the distribution of the number of clips per theme. Figure 11 provides a visual representation of the distribution of time per theme. It can be noted from Figure 11 that the theme with the greatest amount of cumulative time allotted was barriers.

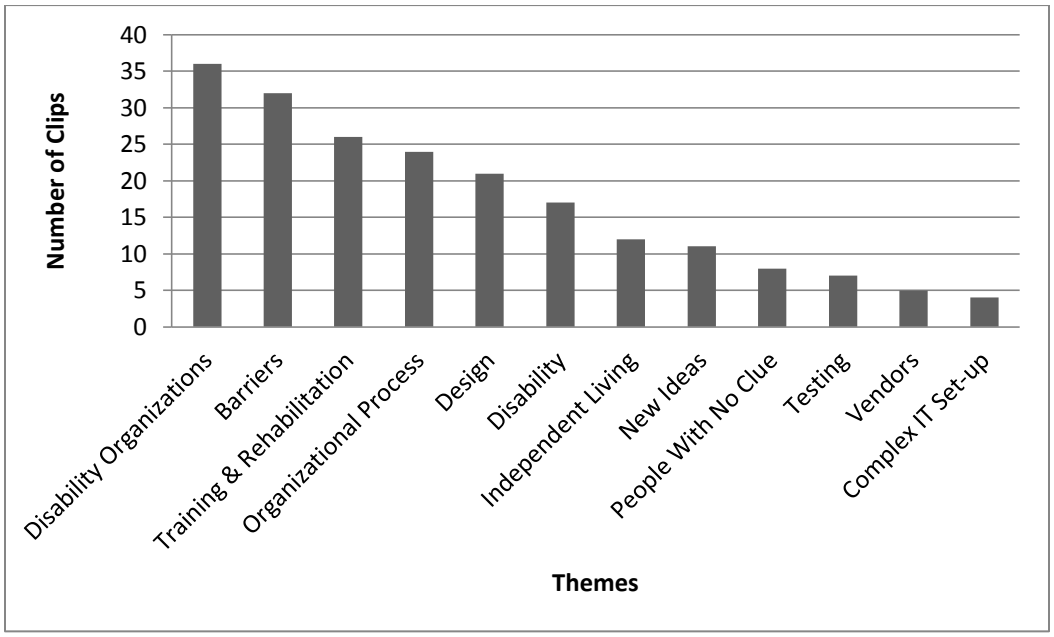

Figure 10. Distribution of the Number of Clips per Theme.

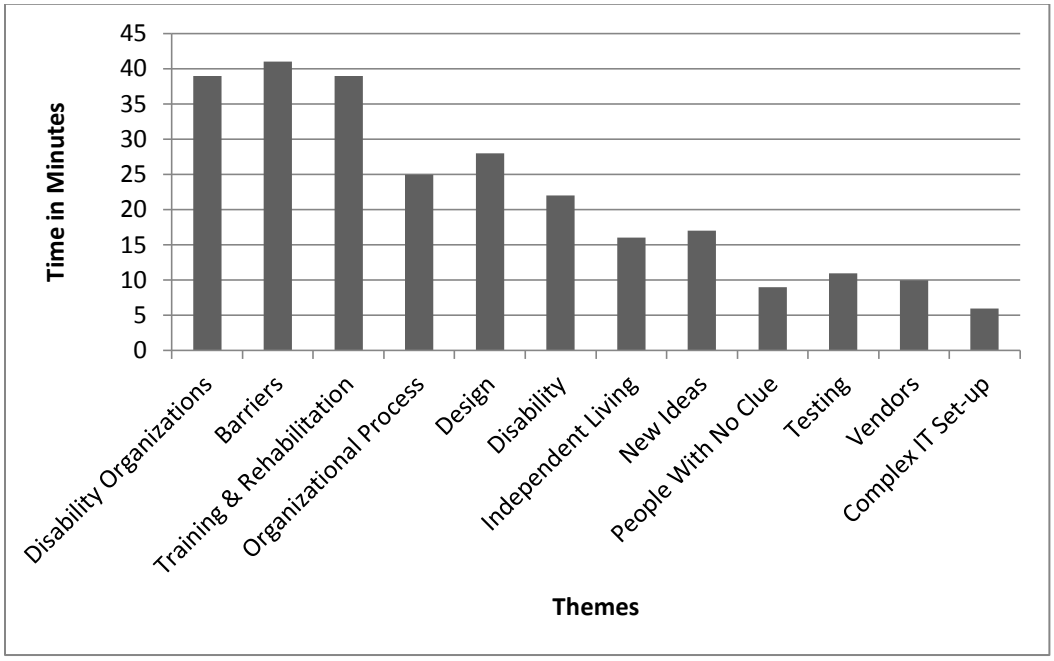

Figure 11. Cumulative Clip Time per Theme

In the Barrier theme there were sub-themes called “Employment”, “Lived experience”, “Media”, and “Volunteerism expected”. There were many clips that were not assigned to sub-theme collections and had clip titles such as, “Social inclusion”, “Administration in education”, “Leary of private sector funding”, “Barriers to advocacy”, “Disability interest wanes when champion leaves”, “Service dog friendly hotel”, Attitudinal barriers”, “Overcome fear and see human beings”, “Everybody is busy”, “Proprietary knowledge”, and “Opportunity to overcome lack of awareness”.

4.5 Relationship between Ecosystems and the Barrier Theme

One of the themes, Barriers, is found within many ecosystems because while only one clip could be assigned to one theme or sub-theme, a clip could be assigned to many ecosystems; therefore, one clip categorized under the Barrier theme could show up across many ecosystems. Whereas the largest ecosystem was Disability Organizations and Communities, it did not contain the highest number of Barrier clips. Instead, the most Barriers coded related to Industry & Business, Day-to-Day Living and Legislation, and Regulations & Governments as summarized in Figure 12.

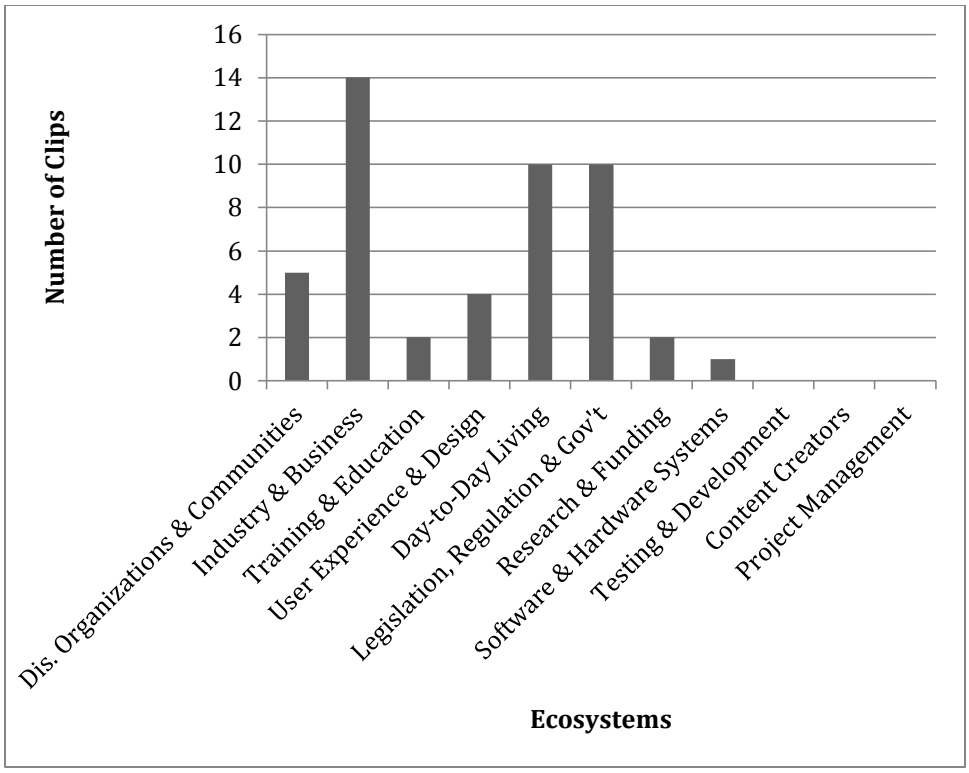

Figure 12. Number of Clips Coded Assigned to the Theme, Barriers by Ecosystem.

One participant spoke of the "biggest barriers to change" and summed up many ideas that other participants had raised:

- "In terms of our disability work I would say the biggest barriers to change are attitudinal barriers--getting business to recognize that this is a significant market and a strong business case as well as a moral and legal case and on the other hand getting disability organizations to let their constituency know that there's now opportunities."

The quotation above was in response to the question, “What would you say are the greatest challenges facing your organization at this time?” The juxtaposition of concepts such as “barriers” and “opportunities” resonated among participants. This sums up the relationships between the problems, the possibilities, and potential involvement for disability organizations. Just as “barriers” and “opportunities” are spoken of together, both dignity violation and dignity promotion are examined together in the next section.

4.6 Selected Themes and Sub-Themes Relating to Dignity

One theme, New Ideas, and two sub-themes, lived experience and volunteerism, stood out for me with reference to dignity violation and promotion.

4.6.1 Lived Experience

Lived experience with disability was referred to by one participant as providing an active awareness of limitations that exist because they are more impacted by an accessibility issues than someone without. This could lead more loss of dignity for people with disabilities relative to those without.

The tension or cultural divide between people with and without lived experience of disability is highlighted with this quote:

- “You know, a vision-impaired Executive Director out there trying to raise money and do things for the organization would just create a whole different perception and people would jump on board a lot more.” ~ Participant

One participant said that many business partners are interested in partnering with a disability organization because someone close to them, perhaps in their family, has a disability. He went on to say that the partnership is really about that experience and not necessarily the organization. The importance of personal experience with disability shapes disability champions in organizations and drives interest in inclusive practices. This ties in with the research from the UK that found that donors choose charitable organizations based more on personal preference or experience, rather than on need (Breeze, 2013).

- “You meet with hiring managers, CEOs, HR and others, they're interested; they're keen. And you may come out with some kind of partnership. But somewhere in the conversation, sometime close to the end or the middle they'll say ‘my son has a disability‘. It is really is about that experience that is really driving the interest. It's not necessarily the organization. It's in terms of their own personal experience with somebody with a disability that generates that interest.” ~Participant

One participant spoke of a colleague who used a wheelchair and a staff field trip to a retreat house. He called the day before the trip to find out if the venue was accessible. He was told yes, they had boards and planks of wood. He asked about the availability of an accessible washroom and was told that the "nuns make do" meaning that the nuns who had disabilities did not complain about the accessibility issues. The colleague declined to attend the field trip. The participant commented despairingly about a "mindset that you've just got to suck it up" if you have a disability and accept day-to-day dignity violations as somehow acceptable.

4.6.2 Volunteerism

Many participants were volunteering their time and knowledge for free at focus groups:

- "People belonging to various disability groups are more than willing have offered our services and our knowledge for free because we want products to be accessible." ~ Participant

But in the same sentence this participant brought up the reality of unemployment of people with disabilities and she estimated that only ten percent of focus groups she attended ever offered her payment. She and other participants questioned the equality or fairness of offering services when consulting companies are paid the "big bucks".

Another participant commented that he feels attending focus groups without payment is considered a civic duty of people with disabilities by government. He would go to meetings as an unpaid disabled person surrounded by able-bodied people who worked for and were paid by the government. The dignity violation here is marked as people with disabilities feel less valued than others.

4.6.3 New Ideas - Raising Awareness

Another participant noted that awareness of accessibility is rising due to the business case that inaccessible businesses are shutting out potential market share. Several participants talked about accessibility standards and legislation as a big component to raising awareness or dignity promotion.

One participant thought that raising awareness has to be subtle:

- "Nobody is going to set up a separate time to learn anything about disability. It has to be included into what they are doing e.g. the coffee hour at the church. It's got to be community education – community-based education."

Another participant talked about community sharing of technical information and capacity building by creating an all-purpose disability hub where regardless of the question or service one could go to this

location and gain insight into what is needed to provide it. The hub would contribute to dignity promotion.

4.7 Summary and Reflection

This section introduced and described key findings from the research. Eleven ecosystems and twelve themes were identified. Their relative importance to the participants was shown in terms of number of audio clips and length of time devoted to each. Participants' views on individual ecosystems and some significant sub-themes were presented. The relationship between ecosystems and themes was illustrated using Barriers as the sample theme.

From the very first interview, I heard about troubling issues that I had not considered. Naively perhaps, I did not realize that a disability organization could have a significant negative impact. The first participant talked about one disability organization as "single-handedly responsible for doing far more to hold back the evolution of blind society in Canada than it's ever done to promote it".

As a sighted person listening to this, I was shocked. My response during the interview was "Oh dear". I realized that I needed to learn more about how disability and accessibility issues impacted people as individuals. As a sighted person I had assumed that disability

organizations representing blind people were endorsed by all blind people. My research response was to seek the assistance of an advisor versed in disability studies who could help me understand why I lacked awareness of this issue.

Another statement that shocked me was when one participant told me about going to a focus group earlier in the week for a disability organization. It took her an hour to get there and she had skipped dinner to provide “all this information to them” and “got nothing”. She told the people that sponsored the event “I am not working” and asked them for some coffee cards from Tim Hortons. She said they refused, and when she asked for coffee cards the other participants who also had a disability “shot her down”. Looking at the transcript my response was “wow”. I had not considered that disability organizations could divide their constituency.

Another surprise occurred during the first interview when the participant talked about the extremely high unemployment rate for blind people in Canada and mentioned a friend from Eritrea who said, “At least in Eritrea they teach blind people how to sell chickens in the market. If I had known what it was like here, I would have stayed home.” The participant spoke of independent living, the need for training in order to have a place in “mainstream” culture, and how

technology, specifically the iPhone can “level the playing field”. With the iPhone “You’re not weird anymore and you’re cool like everybody else. And what does that do? It makes people forget that you can’t see or whatever.”

I knew nothing. I had dipped my toe into an ocean and had begun to uncover something much more vast and fundamental than the initial research question.

Ecosystems and themes were two different analytic approaches to examine the role of disability organizations. Ecosystems could be possible segments of the economy where inclusive design efforts could be directed since these segments emerged as being important to the participants. Themes and sub-themes are values that could direct various products and services. Across all these, dignity promotions and violations came out as an underlying theme. This aspect is described further in the next section.

5 Discussion

Instead of objectivity, Corbin and Strauss (2015, p.79) say that qualitative research grows from sensitivity that enables researchers to see connections between concepts. It could happen after waking from a dream or by insight stimulated from another experience. The arrival of a “core category” (Corbin and Strauss, 2015) is what a researcher considers to be the main theme of the research.

A core category, as described in Corbin & Strauss (p. 188, 2015), is the determined main theme of the research. It underlies every theme, and is broad and abstract in order to represent all the participants in the study. Dignity was the core category as expressed by participants with stories of both “dignity promotion” and “dignity violation” to use the dignity taxonomy of Jacobson (2009) described in section 2.3.

This finding is substantiated by the fact that dignity as a human value finds place in legislation and literature as discussed below.

Ontario has two pieces of human rights legislation that use the word “dignity”:

1. The AODA Standards for Customer service (Government of Ontario, 2005b) which states: “goods or services must be

provided in a manner that respects the *dignity* and independence of persons with disabilities."

2. The Ontario Human Rights Code (OHRC) (Government of Ontario, 1990) "…it is public policy in Ontario to recognize the dignity and worth of every person". The OHRC has primacy over the AODA.

The principle of dignity is discussed in an AODA guide (Government of Ontario, 2009) that explains that people with disabilities are "valued and as deserving of effective and full service as any other customers", and should not be forced "to accept lesser service, quality or convenience". Dignity is very closely tied with the concept of inclusion. In terms of technology and inclusion, Goggin writes (Goggin & Newell, 2007) that "People with disabilities still face a long struggle to be accepted in society, as equal members of their national communities and cultures".

5.1 A Model with Dignity as a Core User Value

My core finding was a deep need for dialogue and understanding about the dignity violations and dignity promotions experienced by people with disabilities. Despite human rights legislation, dignity violations were acutely expressed by participants especially in the

areas of volunteerism, barriers to employment, and the challenges of living day to day with a disability.

I realized after I started that interviews that I had made two wrong assumptions. The first assumption was that one disability organization could cover all areas of accessibility.

Initially I thought that disability organizations could set up their own testing and design programs. After the interviews and realizing the different mandates of disability organizations, I realized that partnering or a consortium would be a better alternative to take into account the diverse perspectives of accessibility.

- “Partnering with like-minded organizations [will enable disability organizations] to create an offering. So, for instance, an organization that provides services to those who are blind and organization who provide services to those who are hearing impaired, and an organization that provides services to individuals who have mobility concerns--those three organizations coming together as one service offering that they could then use to approach a larger organization in all of those regards.” ~Participant

The second assumption was the disability organizations spoke collectively for all their constituents. Disability organizations may lose

constituents for many reasons. The participants in the study had both a mix of positive and negative experiences with disability organizations and some were no longer associated with an organization. Some revealed that they had been with a disability organization for a time in their lives, and then they had moved on. In the future, it may be essential for disability organizations to draw on the skills of individuals who may no longer consider themselves constituents to keep up with technology.

My participants indicated that accessibility is so complex, no one organization or person has all the answers. In addition, with social media today, one person could potentially have more influence than an entire organization. Individuals who are not associated directly with a disability organization may have a great deal of knowledge to share.

Therefore, the model is much different than I expected because I found a deeper need for dialogue about dignity and what that really means; what if system design considered dignity first, before compliance? For instance, is it dignified to have to go through a back door all the time? Is it dignified to be unable to eat in the same restaurant as friends? In that context, the AODA and other legislation doesn't seem to go very far at all because many of these dignity violations are still happening despite having legislation in place.

The other element of dignity that many participants spoke of is volunteerism and the expectation that they assess accessibility of products or services for free while people without disabilities doing the same thing are being paid.

In turn, there are a large number of people open to learning about accessibility and disability, but they don't encounter people with disabilities in their everyday lives and that's problematic. Many people have never met a blind person or a deaf person because they have never had the opportunity. Sensitivity and knowledge is built up through daily interactions with loved ones and friends. For young people in the educational sector, accessibility is not woven into the curriculum. For instance, in carpentry class, are students exposed to the accessibility benefits of rounded corners on tables, counters, and chairs?

The other element I feel needs to be part of the model is trust. Trust is very important to bring together those open to learning and those willing to share. How is trust built up and achieved? I believe trust is achieved through the small, gentle, day-to-day interactions of daily living.

A worded description of the model image (Figure 13) is: there are three circles--An outside circle, an inner circle and a core inner circle.

The core inner circle is labelled "dignity". Surrounding the core is a circle of alternating people and organizations representing a community of practice. Between this circle and the outside circle is trust that enables gentle day-to-day interaction.

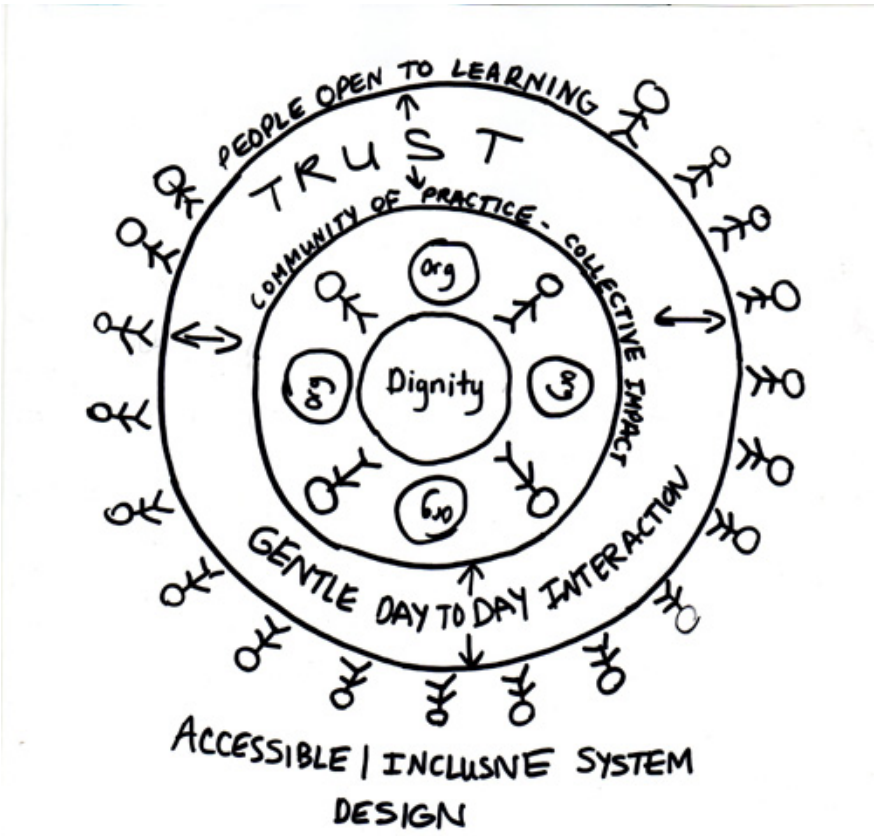

Figure 13. Accessible/Inclusive System Design Model

5.2 Participant Feedback

I reflected the idea back to the 12 study participants to get their input and further thoughts. I called the reflection a model which in design

might be referred to as “conceptual model” in order to move a design idea to the next phase. As Rogers, Sharp and Preece point out (2015 p. 400) “The first step in getting a concrete view of the conceptual model is to steep yourself in the data you have gathered…and try to *emphasize with them*”.

The model was emailed to the participants with this description: “accessible/inclusive system design should have dignity at its core. Surrounding the need for dignity is a community of practice consisting of both organizations and individuals. The next level is trust, necessary to create engagement (dialogue or gentle day-to-day interactions) between people open to learning on the outside.”

Of the 12 participants, 8 responded. The participants said:

- "It sounds to me as though you've hit the nail right on the head.”
- "I think you are hitting on a very interesting and important idea, keep going! I love the phrase 'dignity first, before compliance’ - that is so true and you should keep trying to work toward a concrete design conclusion based on this.”
- “This really is quite excellent and I think you've squared the nail with the dignity stuff. What will you do with these concepts/conclusions now?”

- “Following up, I've had the chance to review and read the though the attachment you sent a few times. Well done! I think you've captured the concept brilliantly. In reading through the concept, I had the initial thought that - of course that's it! Disability organizations have for so long worked in silos, thereby not recognizing the effectiveness of a community of practice to promote a greater understanding and environment for learning while keeping a focus on dignity and thereby initiating trust. I suppose that the next question is in regards to the community of practice and how you envision its creation and development.”
- “I think this is accurate and thoughtful… I like the focus on dignity.”
- “I think the model is great. I liked the idea of promoting dignity. And respect for dignity as part of inclusion."
- “Your overview of developing inclusive design sounds wonderful! There are many parts to the equation, aren't there? … The whole concept of dignity before compliance is key. Isn't it sad that it gets maybe not forgotten, but often put on the back-burner?”

Some insightful analysis of the model:

- “Thanks for following up with me. As for the model, it sounds pretty simple. Did I miss anything other than the two levels of dignity and trust? How does this help people with disabilities market their skills for income generation? I thought that was the end goal of this project.”
- “I am also inspired (challenged) by the notion that the field is very complex - it is as nuanced as the human species, in fact, so how can we design systems to handle that complexity? The key though is how dignity is made real, given that we are talking about individual needs and many of those individuals are not yet empowered to take charge of redesigning their lives.”
- “I suppose that the next question is in regards to the community of practice and how you envision its creation and development. Would there be a centre nucleus or a hub that could act as anchor? Would there then also be multiple hubs to focus on different concerns or it be logical to function solely with one as an overarching and neutral body?”
- “I think the one false note is when you say accessibility is complicated. I know what you mean in a broad sense but people may read this to me that modifying the built

environment is technically complicated for example. I don't think you mean this and I would tweak the language."

- "What are the next steps? What's an example? Does something already exist?"

Of course, it is reassuring that the idea of dignity at the core seemed to be confirmed by the participants, but that has opened up further questions. What does dignity really mean? How does dignity in critical disability studies mesh with empathy in the context of design?

Many participants wanted to know what's next? What action can be taken as a result of this study? This leads to future research needed about empathy and dignity and an example of a web application that considers dignity.

5.3 'Inclusive Teacher' - A Showcase Web Application

Part of my research objective was to identify a suitable project to help rectify barriers. Originally I had planned to identify a project outside of my research. Instead, during the research process, I designed a web application (app) during data analysis as a way to understand and address barriers that the participants were raising. This app is a tool for dialogue and as raised in the findings of the study, the app considered the need for dignity, revenue generation, sharing of lived experience, raising awareness, and targeting of technical skills.

“Inclusive Teacher” is a web app designed to establish connections between instructors wanting to deliver inclusive education experiences with people with disabilities looking to share their know-how. Lived experiences can be shared in the context of learning; however, the need to share personal stories is not required. Instead the person with disabilities is a dignified collaborator who might work with a carpentry instructor to provide context to a class about rounded table edges or perhaps a developer teaching accessible programming.

The app will provide people with disabilities an opportunity to earn income and promote personal growth and achievements. In addition, the app will support education and learning based on the needs of a wide cross-section of society across a range of academic disciplines. It will also provide policy makers and advocates of inclusive design with a practical tool to build community and understanding.

“Inclusive Teacher” will promote meaningful employment and self-development in addition to promoting a best practice model with dignity at the core. The app would initially be deployed for the education sector, but could be adopted for a broader career match audience of employers. See figure below for a sample home page:

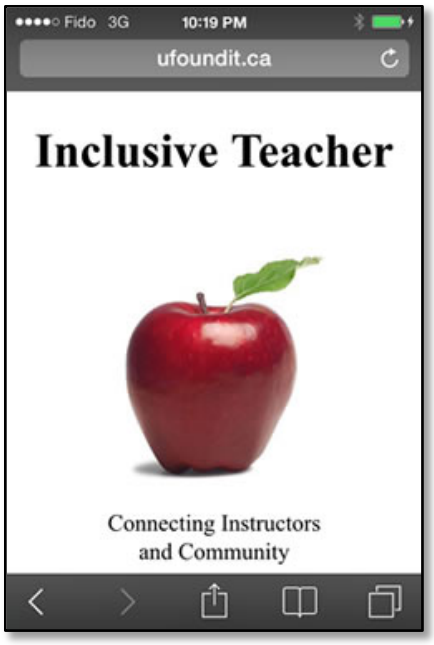

Figure 14. Home Screen of "Inclusive Teacher" Web App.

5.3.1 Context Within the Education and Training Ecosystem

People with disabilities comprised 15.4 percent of Ontario's population in 2006 and face reduced access to education and income. In 2006 people with disabilities earned 28% less than people without disabilities and education attainment of people with disabilities is significantly lower (Kemper et al., 2010)

Ontario has enacted legislation, the Accessibility for Ontarians with Disabilities Act (2005), with the purpose to rectify discrimination that people with disabilities have experienced and to enable full participation in society. The model of achieving accessibility through

compliance drives action to an extent, but is far from ideal. In fact, the AODA Alliance, a watch-dog organization that monitors government enforcement of the AODA for compliance, noted that the Ontario government is not effectively enforcing the law (2013). A downside of legislation is that it tends to be punitive in nature which negates the intent of the legislation in the first place.

At the same time, the model of higher education delivery is changing. There is a trend toward more on-line learning at a lower cost and increased adoption of innovative business models to help fund institutions (The Association of Universities and Colleges in Canada, 2013). It is necessary to integrate the skills and knowledge of people with disabilities into higher education especially as higher education continues to look for innovation and creativity.

Storytelling has been a method of communicating the stories of people with disabilities to the public, particularly for fundraising for disability organizations. Telling compelling tales of people with disabilities has been a successful method of fundraising, but the downside is individuals may be further marginalized by being defined by disabilities rather than abilities (Costa et al., 2012). There is no skill or innovation exchange. A fuller participation by people with

disabilities in society is needed to increase dialogue, dignity, understanding, creativity and economic impact.

5.4 Inclusive Teacher Site Architecture

The site is modeled on Kijiji, a popular classified advertising site (Wikipedia, 2015). It will be divided into five areas as illustrated in the figure below:

1. Post an Ad
2. Search
3. My Inclusive Teacher
4. Watchlist
5. Settings

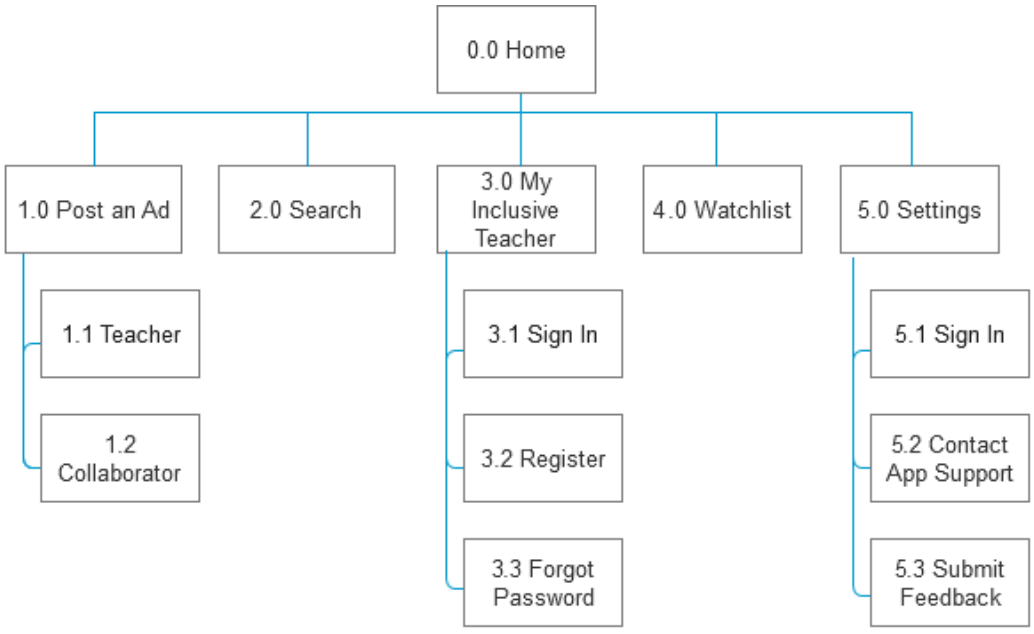

Figure 15. Site Architecture Diagram of Inclusive Teacher.

The system architecture is described further below:

(1.0) Post an Ad

After an initial home “splash” page the user will be re-directed after 3 seconds to 1.0 “Post an Ad”. On this page there will be two buttons:

- 1.1“Teacher”
- 1.2 “Collaborator”.

They lead to different forms where an ad can be posted with the following fields as indicated in Table 4.

Table 4. *Attributes of a Teacher and Collaborator*

1.1 Teacher	*1.2 Collaborator*

• Level/Year (text box)
• Subject (text box)
• Looking for:
  o Class visitor/curriculum building/etc(checkbox)
  o Hobbies (text box)
  o Skills (text box)
  o Unique experience (text box)
  o In order to (text box)
	• Areas of expertise(text box)
	• Personal Experience(text box)
	• (Optional) Disability Organization Associated with (dropdown box)

(2.0) Search

This page will allow the user to search for an ad without registration being necessary.

(3.0) My Inclusive Teacher

This page will enable the collaborator to formally register if he wishes to set up a formal payment arrangement with the institution.

(4.0) Watchlist

This page will display any saved searches.

(5.0) Settings

This page will display buttons to further help, login information, feedback, privacy information, and other settings.

5.4.1 Payment Model

A key element of the app is to ensure dignity for all users, particularly collaborators who may be persons with disabilities or their caregivers/assistants.

Collaborators do not need to register to post and view ads. They only need to register to receive monetary payment from the institution.

As illustrated in Figure 16, if the instructor and collaborator find a suitable match, they proceed to the institution or network of schools for further steps. Ideally the network of schools or school board will be the funder of this initiative or receive funding for this initiative from government or an interested funder.

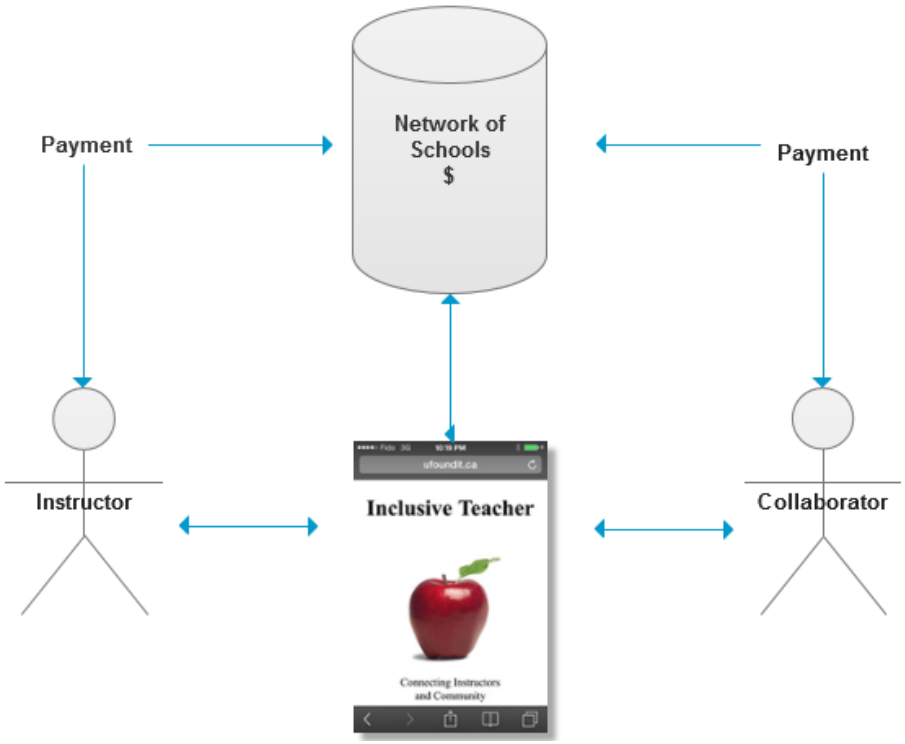

Figure 16. Potential Funding Model.

5.4.2 Response to the Need for Dignity Promotion

1. Dignity promotion a priority during initial conception

   The app will provide a tool for educational communities to engage with a wide audience of individuals. Collaborators will be paid fairly for participation by the institution. Dignity was considered first priority in early design based on responses from the participants in the study.

2. Meaningful engagement and interactions

   "Inclusive Teacher" will empower people with disabilities to meaningfully engage with educators and students on topics of

relevance to learning, e.g., in a carpentry class there can be discussion about rounded table and chair edges for safety purposes and why that is important. Perhaps the collaborator is a skilled carpenter with extensive knowledge on the topic.

3. Higher education partnerships

   "Inclusive Teacher" will open up a possibility for partnerships between educators, businesses, and disability organizations.

5.5 Limitations of the Work

This study proved difficult. The outcome of dignity was not a concept that I had even considered when designing the research methodology. I shifted from looking at how disability organizations could profit to wondering if they should profit at all, to realizing that each organization has its own mandate and that inclusive design could help each organization fulfill its mandate by maintaining and advancing the dignity of its constituents and by extension all people.

User-led disability organizations are diverse with varying mandates. Due to time constraints and the shift of focus, this study does not investigate disability organizations in terms of their nuances, roles or advocacy. The limitation of trying to combine two very distinct and usually separated areas means both areas are not covered with the

depth and breadth that they both deserve. Even while writing this paper and getting it reviewed by screen reader users, problems were encountered with the accessibility of a third party plug-in I was using. I contacted the company to find out whether their product had been tested for accessibility in MS Word. The response from an employee was:

- “Unfortunately the plugin has not been tested for accessibility with screen readers, so issues may occur. I have brought this to the attention of our developers, but we have had reports for years, so I am unsure when this will actually be worked on. Apologies for any inconvenience this may cause you.”

This response highlights the day-to-day dignity violations faced by people with disabilities. The developers have known their software is not accessible for years and yet they regard the issue as low priority and as just an inconvenience. Screen reader users will just have to “make do”, like the nuns in the participant’s story in section 4.6.3. The question is how do you raise awareness with developers and let them know that even though this issue is low-priority to them, it’s a matter of dignity to others?

After speaking to 12 participants, there was a plethora of data, but due to the limits of time and scope, I had to pick and choose which

ideas to bring forth. The model provided in this study is only one of many possible models that could have come from the data. In the same way, the web application is only one example of many possible apps that could be developed to promote dignity.

Due to time and scope limitations, I concentrated on the core concept of dignity for the model and did not elaborate on any of the other principles such as the community of practice, trust or people open to learning.

5.6 Contributions to the Field of Inclusive Design

My project began with investigation of a business model, but after the interviews and movement towards a core category, the research shifted from a business model to a dignity model. My project used grounded theory to investigate a business model for disability organizations to participate in inclusive design. Through a series of interviews, a core category developed which placed the consideration of dignity as a key concept in the inclusive design process. From this key finding a model has been developed that places dignity at the centre of an accessible inclusively designed system. I produced a web application to showcase how this model could be applied in an education and training ecosystem.

My research used a grounded approach to discover the value that participants directly and indirectly concerned with disability placed on dignity. My model and showcase web application could be a platform for further research into the role of dignity in inclusive design and provide a new avenue of thought. In addition, the role of the web application was to draw out theoretical thinking.

Promoting the dignity of the user appears to be a useful principle for inclusive design. Like with most other inclusive design principles, this too offers a curb cut advantage in that such a design would appeal to all users irrespective of abilities because dignity is a fundamental, universal human value. I'm hoping that this study will start a conversation that may not have existed and open up to a plethora of research and research approaches to further examine dignity in design. If my study can do this this, it would be wonderful contribution.

5.7 Next Steps and Future Research

The participants highlighted the importance of dignity. This showed, interestingly, that empathy is what the designers need to bear in their minds while engaging in inclusive design and in order to provide a good user experience, the design should promote the dignity of the user. Using the taxonomy of dignity (Jacobson, 2009) in more depth,

it would give concrete language and a framework to shift mindsets. I believe it would be possible to do further studies exploring the role of dignity promotion in inclusive design user experience. Perhaps a quick and simple scale, similar to John Brooke's System Usability Scale (Brooke, 1996) could be developed to assist designers and developers to recognize dignity or lack thereof in their designs from the outset.

I only concentrated on the centre core of the model and did not elaborate on any of the other principles such as the community of practice, trust or people open to learning that would facilitate dignity promotion. These areas require further examination and research.

The next steps with regard to the showcase web application would be to create a prototype that could open dialogue and co-design. It would be necessary to involve people of all abilities in its development and ensure that accessibility is considered in early prototyping and in development stages.

6 Conclusion

Inclusive design is a flexible practice that engages the involvement of users with diverse needs at the heart of the design process. Criteria and principles are flexible with the underlying goal being to produce a design for the benefit of all. This design would be based on insights from a specific user or group who might otherwise be excluded.

This major research project explored the role of disability organizations in the inclusive design process. Disability organizations were defined narrowly as non-governmental organizations that provide services for people with disabilities. Of two types of disability organizations, user-led and non-user led, this research focuses on organizations that are non-user led where there is not a strict policy to include people with disabilities in the leadership.

The initial focus of the project was to explore the possibility of disability organizations using their expert knowledge of the challenges of living with a disability to engage with businesses to produce better products and services through inclusive design.

Open-ended interviews were held with twelve participants representing interactions with disability organizations as clients, employees, volunteers, supporters, or business associates. The

participants also had prior knowledge of disability and disability organizations, but otherwise were vastly different from one another.

The data were gathered and analyzed using a grounded approach. Interviews and analysis of the data were happening at the same time. Raw interview data were coded in a variety of ways by extracting interview segments called clips and assigning them to categories with both broad and specific meaning.

The analysis revealed the complexity of accessibility and the value associated by the participants with dignity. The inter-connected worlds of accessibility are discussed and classified into eleven ecosystems. Findings show that accessibility is very complex and context-specific. In light of the complexity of accessibility, a common core theme seems to underlie the complexity. The core theme revolves around both dignity promotion and violation. A conceptual model with dignity at the core was shared with participants to receive their input. Participants were receptive to the core finding, and wanted to know next steps to move the research forward.

A broader analysis of ecosystems revealed the broad viewpoints discussed across all the interviews and also identified possible areas for focusing design efforts.

A more specific analysis revealed twelve themes and further sub-themes that were identified as concepts that mattered to people with disabilities.

A showcase web application called “Inclusive Teacher” was designed for the Training and Education ecosystem, to facilitate persons with disability to connect with course instructors and assist in providing inclusive education for remuneration. In this way a dialogue is set up within the ecosystem allowing a rising awareness about accessibility through skill exchange.

A core idea proposed by this research is that design, when directed at promoting the dignity of the users, could enhance their experience and create more inclusive systems for everyone.

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Appendix A – Self-Reflection on Disability Experience

I first witnessed disability through a child's eyes—my own. When I was a baby my grandfather John had a stroke that left him paralyzed along the left side of his body. He never walked again. I saw wheelchairs, hospitals, nurses, and orderlies from a very young age.

John's stroke was a milestone for my family. My grandmother referred to it as "when John took sick". Before his stroke, he gardened, cottaged, drove, was involved with amateur hockey and was otherwise enjoying his retirement. After his stroke, everything changed. I only ever knew him in a hospital setting. He would lament about this to my grandmother-- that my only memories of him will always be of a hospital.

After the stroke, my grandmother initially nursed him at home for two years, but in the end, could not keep it up and John eventually was moved to St Vincent Hospital in Ottawa, about 50 miles from home.

We spent every holiday in the hospital, but my brother and I made our own fun, going down to the small cafe for treats, and pushing the wonderful leather chairs that had wooden handles around the big solariums. We made friends with the other patients. Most vividly I remember the "La La Guy"—we called him that because when he would see us, he called out "La La" in excitement. I learned later that he had been a car mechanic and a car had fallen on him. I don't know if he had many visitors, but he was always happy to see us. I didn't realize I was witnessing disability, and wasn't bothered at all by people sitting in wheelchairs or hearing people call out. It was just the way things were there.

My memories of the hospital are positive. My grandmother never worried about the care. It was excellent. Three orderlies would come several times a day to re-position my grandfather and attend to all needs. My grandfather had a triangle hanging from the ceiling that he would use to lift himself up.

I remember going out into the garden in the nice weather where they was a lovely garden swing. When it was time to go home, it was always sad. It was hard to understand why we couldn't just take John home with us.

Prior to the stroke, John was "lame" which meant he walked with a limp and had a cane because he had been run over by a wagon when he was eight. He spent four years in the Toronto Sick Children's Hospital. He had lived with disability practically his entire life.

In the early 1900's, Sick Kids patients were taken to the [Toronto] Island during the summer, as it was cooler due to the breeze from Lake Ontario. It was there that he took his leg brace off and learned to swim. His strength grew and he returned home alive instead of "in a box" as he overheard someone say when he initially was hurt.

When he did return, he was four years behind in school. A lady in the town tutored him to catch up with his peers. He started delivering newspapers on foot through the town to make money. One day he was looking at a bicycle in a store window. A man asked him how he liked it. The next thing you know the man came out of the store with the bike and told him it was to help him deliver the papers. These acts of kindness had a long-lasting effect on my grandfather who did a great deal of volunteer work later in life, especially raising money for boy's hockey equipment. His motto was "champion the underdog" since he grew up without a father and with a disability. After he caught up in school, he excelled and studied to become an accountant.

I was surprised to learn that my grandfather was lame. My mother had never mentioned it, and never used that word. I don't think she ever saw her father's disability; she only saw his abilities and was very proud of him. My grandparents were very social, high-energy people and I think I discovered my grandfather's disability because my grandmother kept his cane, long after he had any need for it.

Yet despite John's perseverance, the stroke took its toll. My grandmother had to sell the cottage, then the house. She never learned to drive and so she took the bus to Ottawa every Wednesday and every weekend. The cost was enormous—the hospital bills ate up

my grandfather's pension and my grandmother went to work part-time for 10 years. People would say to her it was so sad she had to sell the cottage, then the house, but she merely said she had parted with dearer things. She never looked back.

As a child, I didn't realize the sacrifices she was making as a devoted caregiver and partner. My grandmother seemed like the happiest person on earth, and as I got older I loved going down to visit her and John. We took the bus together into Ottawa and I'm still a huge fan of bus travel. Every weekend we would stay with my grandmother's sister and niece – Edna and Barbara.

Edna and Barbara were inseparable. Edna was also Barbara's aunt and caregiver. Barbara was called at the time "mentally retarded" which means she had an intellectual disability. I remember when I was little, going to Barbara's house and seeing toys there, but I didn't realize until I was older that they belonged to her. I didn't realize Barbara was different from the other adults, other than she was more fun – she always played with me. Her speech was hard to understand at times, but other adults were hard to understand also. When I was older and could write letters, Barbara and I were pen pals. She hand printed her letters when all the other adults wrote with cursive handwriting. I was able to read her letters.

As time went on and I grew older, I saw much more of Barbara and Edna. Edna wanted to take Barbara on a summer vacation—a bus trip. She recruited my grandmother who recruited me. Thus, our era of summer bus trips began. Edna and my grandmother were in their 70's, Barbara in her 40's and I was in my early teens. My job was to be the eyes and ears of the group and to take Barbara to the washroom at our many rest stops. Barbara liked to visit the washrooms several times a stop. Edna at this time had developed deterioration of the retina and was legally blind. I became the menu reader at restaurants.

Looking back at it now, I suppose we were quite an odd foursome; but we completely fit in on the Ottawa Valley Tours bus. The trip had a hostess at the front of the bus with a microphone who led sing songs, provided facts and jokes. The clientele were in their 70's and

80’s; so Barbara and I were the youngest travellers by far. Our tours continued until I started a summer job and wasn’t able to get time off. I think they tried a tour without me, but it was their last.

Barbara remained at home until after Edna died and her father was too old to look after her alone. I imagine my great aunt and uncle, were under considerable pressure to institutionalize her as a child which was the prevalent practice of the day from 1930’s – 1970’s (Rossiter & Clarkson, 2013); however, instead, Barbara went to a private parochial school in Ottawa along with her brothers and sister, and stayed in the same grade as her peers regardless of her academic achievement. It was rather forward thinking for the day. Barbara could read and write and was extremely sociable and curious. That doesn’t mean to say that it was easy for the family, but it was obviously a commitment and a challenge that they chose and they never wavered from it.

As my grandmother aged, she too began to experience vision-loss: macular degeneration, cataracts, and glaucoma; I visited her regularly and I remember her turning on the stove and placing her hand above it, feeling for the heat to know what burner to use. Maybe I should have been alarmed at that, but I wasn’t. I would clean up for her and put things away, ensuring to put things in the places where she put things, so she could find them.

One of the activities specifically assigned for me or my brother, was to take her to the cemeteries. She didn’t like asking her friends to take her as she felt it was beyond the call of duty and would definitely be out of their way. She wanted to go to visit the graves of her loved ones, monitor their upkeep, say a prayer, and remember.

She also had diabetes and dealt with the challenge of giving herself daily needles starting at age 80. As her eyesight failed, nurses would load the needles with the correct dose for her and leave a supply in the fridge. She fell and broke her hip at age 85, but took physical therapy to remain at home well into her 90’s. She was an amazing example of how one adapts to barriers and challenges. I remember her struggling to put on panty hose; I don’t think I would have persevered, but she kept on trying until she got the darn things on.

As I reflect, disability has been interwoven into my life. I am in "the space between" as neither an insider nor outsider (Corbin Dwyer & Buckle, 2009) in the world of disability.

Appendix B – Participants

Table 5. *Characteristics of Participants*

#	Interview Modality	Gender	Age	Lived Experience	Perspective	Relationship to Disability Organizations
1	Telephone	M	46-55	Blind	Subject matter expert (SME); Business; Independent Living	Client and past employee
2	Telephone	F	46-55	Blind	Disability Organization	Current employee
3	In Person	M	46-55	Moderately Visually Impaired	Design, Media	Client
4	In Person	F	46-55	Glasses (Mild vision impairment)	Special Needs Educator at Secondary School	No official affiliation
5	Telephone	M	56-65	Glasses (Mild vision impairment)	Disability Organization	Current employee
6	Telephone	F	26-35	Mild hearing loss	Business; accessibility SME; Digital environment	Business to Business
7	In Person	M	26-35	Blind; Echo-location	Business; accessibility SME	Client; Business to Business
8	Telephone	M	36-45	Mildly vision impaired; mildly physically impaired	SME; non-profit sector; business; educator;	Business to Business
9	In Person	M	56-65	Profound hearing loss; Glasses (mild vision impairment)	Educator; SME; business	Client

#	Interview Modality	Gender	Age	Lived Experience	Perspective	Relationship to Disability Organizations
10	Skype	M	56-65	Physical Disability	SME; Business; Non-profit sector; Financial inclusion	Business to Business
11	In Person	F	46-55	Moderately Visually Impaired	SME; Educator	Client
12	Telephone	F	56-65	No functional limitations	SME; Business; Built environment	Past employee

Appendix C – Invitation Informed Consent

INVITATION

You are invited to participate in a study that involves research for Graduate Studies in Inclusive Design at OCAD University. The purpose of this study is develop a business model for inclusive design and testing services that disability organizations could offer to businesses.

WHAT'S INVOLVED

As a participant, you will be asked to participate in a one-on-one private interview. The interview will be about your organization and how you see its role in designing or testing products and services to make them more inclusive. Participation will take approximately one hour of your time.

POTENTIAL BENEFITS AND RISKS

Benefits of participation may include satisfaction from participating in the research to share thoughts and expertise in the accessibility field. There are no known or anticipated risks associated with participation in this study.

Possible long-term benefits resulting from this research are:

- job creation within the disability sector,
- revenue generation for disability organizations,
- viable inclusive design testers for businesses,
- more inclusive products and services created by businesses.

CONFIDENTIALITY

All information you provide is considered confidential; your name will not be included or, in any other way, associated with the data collected in the study unless otherwise agreed to. Data collected during this study will be stored on a password protected laptop and in notebooks. Data will be kept for 3 years after which time the data will be deleted permanently unless specified otherwise. Access to this data will be restricted to the principal investigator and the principal student investigator.

VOLUNTARY PARTICIPATION

Participation in this study is voluntary. If you wish, you may decline to answer any questions or participate in any component of the study. Further, you may decide to withdraw from this study at any time, or to request withdrawal of your data by 1 Dec 2014, prior to data analysis, and you may do so without any penalty or loss of benefits to which you are entitled.

PUBLICATION OF RESULTS

Results of this study will be published in my thesis and may be published professional and scholarly journals, and/or presentations to conferences and colloquia. In any publication, data will be presented in aggregate forms. Quotations from interviews will not be attributed to you without your permission.

Feedback about this study will be available through the Principal Student Investigator, Julie Buelow through email and by phone.

CONTACT INFORMATION AND ETHICS CLEARANCE

If you have any questions about this study or require further information, please contact the Principal Student Investigator, Julie Buelow or the Faculty Supervisor using the contact information provided above. This study has been reviewed and received ethics clearance through the Research Ethics Board at OCAD University, approval # 2014-40. If you have any comments or concerns, please contact the Research Ethics Office through cpineda@ocadu.ca.

CONSENT FORM

I agree to participate in this study called "From Disadvantage to Advantage: Harnessing the Design Power of Disability Organizations". I have made this decision based on the information I have read in the Information-Consent Letter. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time.

Please indicate (check) "YES" for **any** of the options below that apply:

☐ Yes, I agree audio recordings of my interview session to ensure accurate capture of data for further analysis. I am aware that this material will be treated as confidential.

☐Yes, I agree to note taking of my interview session to ensure accurate capture of data for further analysis. I am aware that this material will be treated as confidential.

☐Yes, I agree to be quoted to ensure accurate capture of data for further analysis. I am aware that this material will be treated as confidential.

☐Yes, I would like to hear more about the study.

You may reach me by (provide contact information):

Email:
Postal Address:
Phone:

Name:
Signature: _____
Date:Click here to enter a date. _____

Thank you for your assistance in this project. Please keep a copy of this form for your records.

Appendix D – Interview Guide

STATEMENT OF PURPOSE AND CONFIDENTIALITY

Thank you for agreeing to participate in this research study. My name is Julie Buelow. I'm a student at OCAD University in Inclusive Design. The purpose of this interview is to explore the possibility of your organization providing co-design or testing services to businesses.

Your comments are completely confidential. Your name will not be associated with any comments you make. I will be taking notes and audio recording to record the ideas and comments we discuss today.

This is an opportunity for you to share what is important to you. Please feel free to speak about yourself and your own experiences. There are no right or wrong answers.

Before we begin, are there any questions or concerns?

QUESTIONS (Conversational Method)

I will begin by asking you a series of questions regarding your organization.

Objective (2-3 Questions)

1. What is the main focus or vision of your organization?
2. What are the greatest challenges facing your organization?
3. What is your greatest area of expertise?
4. What is the current funding model for your organization? (Government support? Fundraising?)

Reflective (2 Questions)

1. What is the first thing that comes to your mind when you think about design and disability?
2. Would you say your organization designs better experiences for the people you serve? How?

Interpretive (1-2 Questions)

1. Could you see your organization using its resources and skills to design better experiences for businesses?
2. Could you see your organization partnering with business to provide design or product testing services?

Decisional (1-2 Questions)

1. What suggestions would you make to people who ask for your expertise about designing services and products for everyday use?

CLOSING

Would you like to be contacted for a follow-up interview as the research unfolds and the model develops?

Would you be interested in participating further in this study to test the evolving model?

Appendix E – Demographic Questions

Demographic Info

(Ask participant verbally)

1. What gender do you identify with?

   ☐ male
   ☐ female
   ☐ other

2. What age group do you fall under?

   ☐ under 25
   ☐ 26-35 years
   ☐ 36-45 years
   ☐ 46-55
   ☐ 56-65
   ☐ 66+

Lived Experience

1. Which of the following descriptions best describes your hearing?

1) I consider myself to have normal hearing.

2) I consider myself to have mild hearing loss: Soft noises are not heard and understanding speech is difficult in a loud environment.

3) I consider myself to have moderate hearing loss: Soft and moderately loud noises are not heard. Understanding speech becomes very difficult if background noise is present.

4) I consider myself to have severe hearing loss: Conversations have to be conducted loudly. Group conversations are possible only with a lot of effort.

5) I consider myself to have profound hearing loss: Some very loud noises are heard. Without a hearing aid, communication is no longer possible even with intense effort.

2. Which of the following descriptions best describes your vision:

1) I consider myself NOT visually impaired. I can perform my daily life tasks (such as reading books, watching tv, or use computer) without the need of wearing glasses.

2) I consider myself mildly visually impaired. I need to wear glasses to comfortably perform daily life tasks.

3) I consider myself moderately visually impaired. I have to use assistive technologies such as Zoom Text or Magnifier to read printed or online material.

4) I consider myself severely visually impaired. I am not able to read printed or online material.

5) I have profound vision loss. I am blind. I can only sense light or am completely blind.

3 Which of the following descriptions best describes your physical mobility:

1) I consider myself NOT physically impaired. I can perform my daily life tasks (such as eating, dressing or bathing) and intermediate activities of daily living (walking around the home, doing errands) without the need of assistance.

2) I consider myself mildly physically impaired. I have occasional difficulty performing tasks of daily living assistance with daily life tasks or intermediate activities of daily living, but generally able to manage or overcome these occasional difficulties without assistance.

3) I consider myself moderately physically impaired with frequent difficulty in performing routine activities of daily living, and require assistance with some tasks periodically or continuously.

4) I consider myself severely physically impaired such that I am unable to perform many routine activities of daily living and require assistance with many or all tasks.

4. Which of the following describes your cognitive disposition (thinking/cognition/memory/concentration)?

1) I have no problems with cognitive skills

2) I have occasional difficulties with cognitive skills, but symptoms are generally controlled by medication or behavioral interventions. No disruption in normal daily activities.

3) I have occasional difficulties with cognitive functioning that are not managed by medication or other interventions. There is some disruption in normal daily activities.

4) I have significant deficits in cognitive or intellectual functioning. Unable to consistently work or attend school. Requires assistance with normal daily activities.

Research Profile

Do you identify with any or some of these?

- ☐ Disability organizations (employees, clients, researchers)
- ☐ Design or design industry
- ☐ disability employment specialists
- ☐ business
- ☐ accessibility experts renowned in your fields
- ☐ interested individuals with no direct or formal affiliation with a disability organization.
- ☐ Educator?
- ☐ Government
- ☐ Other _____

Appendix F – Words Related to Accessibility

Table 6. *Words Related to Accessibility*

#	Keyword	Meaning Given When First Recorded
1	“So-called Experts”	Many people call themselves "experts" but who really is an expert?
2	3rd party vendors	[No meaning recorded]
3	Acceptance	[No meaning recorded]
4	Access	Able to get hold of the information and be able to navigate through it
5	ADP	Assistive Devices Program The objective of the Assistive Devices Program (ADP) is to provide consumer centered support and funding to Ontario residents who have long-term physical disabilities and to provide access to personalized assistive devices appropriate for the individual’s basic needs.
6	Advocate	Advocate that people should not give away their knowledge for free
7	AGILE and On-going	Accessibility is moving rapidly and need an on-going approach to keep up
8	AODA	Accessibility for Ontarians with Disabilities Act
9	Appreciate	Appreciate if their opinion sought
10	Art & Science	Accessibility will never be perfect because it is a combination of art and science - we all access and deal with information differently.
11	Assumptions	Assumptions that all PWD use the product in the very same way
12	AT	Assistive technology
13	Balance	Balance struck between what is visually appealing and what is screen reader appealing
14	Budget	Money required to provide basics
15	Buried	As in expertise is buried "deep in the community"
16	Business practice	Businesses are integrating accessibility into their operations and practice

#	Keyword	Meaning Given When First Recorded
17	Can't keep up with technology	[No meaning recorded]
18	Certification	Proof of accessibility credentials
19	Certified	[No meaning recorded]
20	Champion	Accessibility awareness is fueled by a "champion" in the organization. Loses traction if that person leaves
21	Checklist	A list of items detailing things to look for in every project in order that some aspect is not overlooked.
22	Classroom	Accessibility in the classroom
23	Collaboration	Bring together multidisciplinary field together to express need for accessible systems
24	Colour	Relying on colour alone to delegate difference in charts, graphs and images
25	Community	As in "my community" referring to the particular community that the person with disabilities identifies with
26	Complacency	People think accessibility will happen naturally and develop along with technology
27	Compliant	Adheres to regulations
28	Confusing	Decor and layout can contribute to confusion and lack of accessibility
29	Core Competency	Employment and core competency to do the job
30	Cost	Cost is lower if accessibility is embedded in a project early
31	Curb cut effect	Improving an element to make more accessible for one group makes a positive change for everyone
32	Customers	People with disabilities as customers
33	Demand	The demand for accessible solutions is growing with aging population, etc
34	Dialogue	Discussion back and forth to share lived experiences
35	Dignity	Better accessibility training results in customers being treated with dignity

#	Keyword	Meaning Given When First Recorded
36	Disability	Many different definitions of disability dependent on context and place
37	Disconnect or Gap	Attitude or cultural barrier
38	Diversify	Some areas are more difficult to diversify
39	Drawback	As in a feature that might be missing on a device, such as spelling on an iPhone, is a drawback for a person who is blind
40	Duty to accommodate	As defined in Ontario Human Rights Legislation
41	Embed early	Think about accessibility at the start of a project, not at the end
42	Employment	Hire employees with disabilities and retain
43	Enforcement	Regulations to enforce accessibility. How do you enforce the regulations?
44	Expensive	Can't afford training or technical equipment
45	Expertise	People with technical expertise that can train/teach others
46	Fair	Equal access to everyone
47	Feedback	Provide feedback to businesses when given the opportunity
48	Formalized	Guidelines to help PWDs need to be formal in order to match the informal help that PW no disabilities receive
49	frustrating	[No meaning recorded]
50	Ideas	Need a mass injection of new ideas to help community
51	Independent Living	Exploring ways to use technology to enable independent living
52	Insider/Outsider	The culture of lived experience and whether you are an insider or outsider
53	iPhone	iPhone and accessibility features built in
54	Irritating	Irritated when can't access or understand due to lack of awareness
55	Justice	Treat all people fairly

#	Keyword	Meaning Given When First Recorded
56	Knowledge	Knowledge is precious - hard-earned through lived experience
57	Lived Experience	Experience living with an impairment, whether vision, hearing, physical, cognitive
58	Loop	A spatial concept of interaction and vision - not visual
59	Mainstream	Can use the same equipment that everyone else does
60	Meet up	Self-organized meeting of common interest
61	Mismatch	The IDRC (Inclusive Design Research Centre) reframes disability within the design context. Rather than a personal characteristic or a binary state (disabled vs. nondisabled), disability is framed as: a mismatch between the needs of the individual and the design of the product, system or service. With this framing, disability can be experienced by anyone excluded by the design
62	Mobile Technology	Advances in mobile tech and opening up doors to accessibility
63	Myth	Myths about accessibility
64	Networking	Sourcing people for teams
65	Newly disabled	Recently had an accident, disabled
66	OHRC	Ontario Human Rights Legislation
67	Online Access	Types of activities require access to a computer and a network
68	Open Source	Open Source software is freely available
69	Opportunity	Opportunity for discussion to provide recommendations, training, etc
70	Overwhelming	The complexity and volume of information can be overwhelming
71	PDFs	Portable Document Format – open standard for electronic documents
72	Planning	Organizations need to plan an approach to take
73	Poverty	Statistics - over 70% of blind people are unemployed in Canada
74	Prescriptive	Standards need to explain in detail

#	Keyword	Meaning Given When First Recorded
75	Recruitment	Finding suitable candidates for testing and co-design
76	Research models	Shift from medical model of disability to functional limitations model
77	Roadmap	Have a plan on how to institute accessibility polices and processes
78	Robust	The AT software or equipment must work correctly and be reliable
79	SDLC	Software Development Lifecycle
80	Self-identification	Government funding exists for those who "self-identity" and this can drive employment and other opportunities for people with disabilities and other groups at the margins
81	Self-promotion	Promoting skills and looking for employment at all times
82	Sensitivity	Understanding and recognizing different needs
83	Skills	[No meaning recorded]
84	Social Inclusion	Including all people at the table - all people have a chance to participate
85	Social Media	Facebook, Twitter, etc to get message out to networks or groups
86	Standards	Harmonizing and finding the most stringent standard
87	Statistics	Statistics strengthen case for accessibility
88	Storytelling	Experience of disability is in context of other life events and other things happening in life
89	Success	Success is more likely the earlier accessibility is embedded into a project
90	Team	Need a variety of disabilities to build a strong team
91	Technical coding	Accessibility achieved through coding properly
92	Test Scripts	Accessibility must be written into the test scripts in order that it's not left out of testing
93	Testing	Issues with accessibility testing
94	Tools, Resources, Training	Need proper tools and resources in place in order to enact accessibility
95	Training	Technical Training required for people with disabilities

#	Keyword	Meaning Given When First Recorded
96	Under-served	blind and low vision underserved by media -- can't access daily news
97	Unintended Use	Another way of thinking of the "curb cut"
98	Universities	Maybe look to universities for expertise
99	Validation	How do you know if what you created is visually accurate or accessible to others?
100	Vision Required	Problems encountered when vision is required; not perceivable without vision
101	Visual Design	Visual design - does it matter to a person who can't see?
102	Volunteer	People with disabilities are expected to volunteer or offer services for free
103	WCAG	Web Content Accessibility Guidelines
104	Word of Mouth	You find information and people through "word of mouth"