AccessMakers:

A Platform for Inclusive Innovation

by

John D. Willis

Submitted to OCAD University

in partial fulfillment of the requirements for the degree of

Master of Design

in

Inclusive Design

Toronto, Ontario, Canada

cc John D. Willis, 2015

Author's Declaration

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I authorize OCAD University to lend this thesis to other institutions or individuals for the purpose of scholarly research.

I understand that my thesis may be made electronically available to the public.

I further authorize OCAD University to reproduce this thesis by photocopying or by other means, in total or in part, at the request of other institutions or individuals for the purpose of scholarly research.

Abstract

This paper focuses on the feasibility of deploying collaborative user networks to address accessibility challenges faced by people with disabilities. It describes the creation of AccessMakers, a multi-stakeholder design process and online community that supports organizations to identify opportunities for innovation by engaging stakeholders who face access barriers. The author, a designer with low-vision, describes his practice-based research journey from the development of a theoretical model of access barriers as a type of breakdown in service systems, to his effort to re-frame accessibility as a user-, or customer-, experience (UX/CX). The paper includes a review of emerging collaborative practices including open innovation, user innovation, and co-production/co-creation in public services to demonstrate the feasibility of moving beyond regulatory and legalistic approaches to accessibility. Finally, the author describes how he prototyped a storytelling technique to capture access barrier experiences for collaborative networks, and used it as the kernel of the AccessMakers platform.

Acknowledgements

Dedication

For Betty (1936-2012).

And for Amanda, Jacob, and Anna – without whom it is almost all impossible.

Table of Contents

List of Tables

List of Figures

x

1. Introduction: A Journey, and a Map

Figure 1: The Author, or part thereof

This is a report on practice-based research that I conducted between October 2014 and March 2015. Starting from my own experience, I wanted to understand how to mobilize a 'user network' of people with disabilities to address access barriers in a collaborative, open and innovative way.

Starting from a 'design definition of disability', I set myself the task of describing and characterizing the nature of the resulting design space, and specifically how to apply new modes of networked collaboration (exemplified in the 'maker movement' and models of 'outside-in' innovation) to accessibility. The challenge required investigation of both 'what' is being designed, and 'how' to engage different people with various needs and knowledge in collaborative arrangements. I ended up prototyping a general design approach that can be deployed in user-networks of all kinds, including face-to-face or online communities.

This is not a pure research report, but rather a report on an iterative design process. As such, it is often recursive, doubling back on itself as for example when the storytellers in Section 5 confirm and expand on the findings in Sections 3 and 4. I was concerned about a big issue and spent two full design cycles learning how to frame it as a specific design problem – increasing the resolution

on the image, so to speak, by prototyping parts of an overall system and learning from users what 'success' might look like.

My journey is laid out in this introductory 'roadmap'– readers may follow along with the icons in the diagram to the right. This diagram is a deliberate play on the spiralling nature of the design process, in which one iteratively returns again and again to defining the problem and a set of
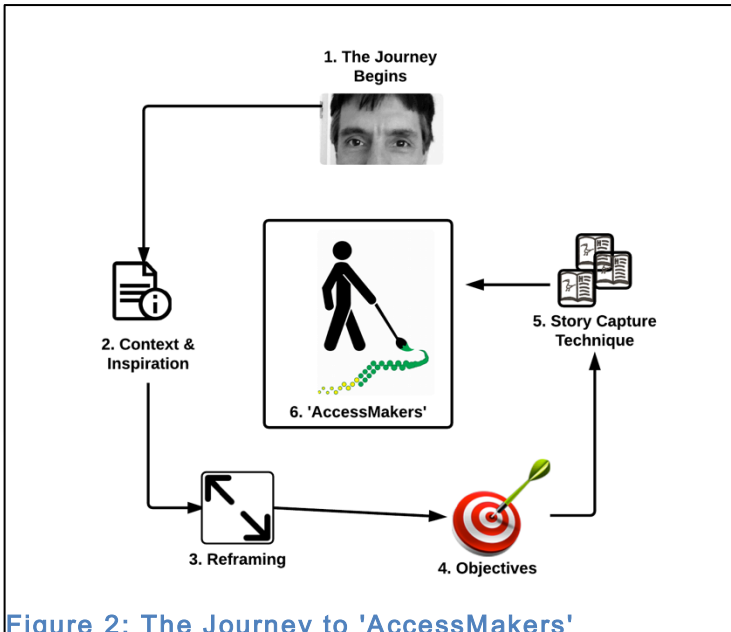
Figure 2: The Journey to 'AccessMakers'

criteria for a solution. In my journey diagram, the first step is highlighted with an image of my own two eyes (denoting my observation of the situation) and concludes with a modified accessibility symbol in which the classic 'blind man' wields a paintbrush or stylus (denoting a new iteration of myself – that of a creator and designer).

Context & Inspiration (Section 2)

The journey begins with my own experience, as a designer who has gradually lost most of his eyesight over a period of 37 years. My experiences led me to

think more deeply about how we can achieve full accessibility for people with disabilities. Using the concepts of *affordances* and *flow* as these terms have emerged in the design disciplines, I cite a number of my own experiences and conclude that access barriers are understandable as user experience and can therefore be called *access experiences.* This finding leads me to the idea that if we want to design for greater access, *we* should adopt design approaches -- such as interaction design and service design -- that are suitable to designing for experience.

Reflecting on a particular access experience in my local bakery, I realized that most of my access experiences are embedded in networks of relationships, actors, and organizations - the bakery is a service system, and it sits within a larger system (company), which sits within an even larger system (sector, city, food culture, economy) – each of which is made up of people, processes, and resources in specific 'designed' configurations. Change is not just about design, no matter how sophisticated; it is often also about aligning decision-makers and accountants, procurement or marketing specialists, engineers, logistics experts, or plant managers. Rarely is a barrier a simple result of my abilities interacting with a discrete object, and therefore solutions need to be sought in relationships between people with varying authority, knowledge, concern, and ability to make change.

These findings also help me to reframes accessibility laws and regulations in terms of design outcomes. To the extent that we frame this challenge as a job for

regulators setting legal standards, we often overlook the extraordinary diversity of experiences that arise from having differently-abled bodies, and we privilege institutions over people. As a result, accessibility is often viewed as a burdensome cost (by those required to meet legal standards), and, at the same time, an approach that yields unsatisfactory results (for those of us who need greater access).

I then explain the alternative approach available in the emerging field of inclusive design, which views accessibility as a process that must be led by the people whose lived experience is historically sidelined or submerged. Inclusive design benefits users both in the creation of new products and services, and in greater levels of civic and economic engagement through the design and innovation process.

This section finishes with a challenge: How can I connect myself to the systems I encounter? How can my voice be heard, and my insights about what needs to be fixed valued, in a design process that works at scale to influence behaviour at a systemic, or organizational, level? What would that look like?

New Frames to Design for Access (Section 3)

With this first iteration of the challenge set, I wanted to get a better understanding of what we are meant to be designing when we are 'designing for access' (the term I introduce to distinguish the application of inclusive design to

the resolution of access barriers, contrasted to common notions of accessibility, which are associated with standardization and the search for so-called universal design solutions). What methods might be most appropriate to these collaborative design tasks, and what platforms might support them most effectively?

I found a very useful conceptual framework in recent literature around the changing nature of our economy, specifically the shift to what is called a *service-dominant logic* in the marketplace. This perspective emphasises the extent to which services emerge from collaboration between users (who bring needs, time, and other intangible resources) and providers (who bring traditional capital, labour time, and knowledge). As a result, it is impossible to separate the production of value from the individual experience of that value, which means that preferences, feelings, expectations, memories and dignity all play a role in how value is realized.

Through this lens, accessibility is on a continuum with usability in general. Since all customers and citizens need access to the diverse flow of value-in-experience that makes up our economy, a person with a disability is not 'different' than the 'mainstream', but rather someone whose 'edge case' user-experiences can spur innovations that benefits a much larger community of consumers or citizens (known as a 'curb cut effect').

John D. Willis

And with individual preferences in the foreground, virtually all actors in both the

public and private sectors are under pressure to give their 'users' (citizens,

customers, patients, transit riders, subscribers, etc.) more influence to design

their own preferred experiences. Imperfect though it undoubtedly is, a

participatory culture is becoming the norm. Converging with the availability of

easy-to-use and/or open source software, hardware, and online platforms, these

developments are spawning a wide array of approaches from crowdsourcing on

the web to 'open innovation' by large companies, that are disrupting old patterns

and blurring the line between producers and consumers (reviving the 1970s

concept of the *prosumer* – a person who produces what they consume).

Design Objectives & Methods (Section 4)

These larger social and economic trends may be game-changing for people with

disabilities because they converge around the potential for network of user-

collaborators to combine the lived experience of barriers with skills, knowledge

and capital to enable the co-creation of 'preferred' access experiences. It is now

technically feasible and key stakeholders are growing accustomed to the

practices and rewards of collaborative design.

A key question is how to mobilize the context-dependent, granular knowledge

that this group of users possesses so that collaborative networks can be formed.

The collection and use of user requirements needs to be done in a way that is

truly inclusive for people with disabilities, positioning them as user-

collaborators rather than (as traditionally) narrowly-conceived 'end users' or passive consumers.

A second consideration is that while seeking solutions that are beneficial for people with disabilities, there should also be benefits to other stakeholders/community members. Embedding inclusive innovation into existing or emerging mainstream practices is critical for success - without intrinsic motivations, serving the interests of people with disabilities will remain an added cost and therefore an after-thought.

I set the following objectives for prototyping – we need platforms or processes that:

1. Mobilize and aggregate 'lived experience' of people with disabilities while maintaining the individual's personal agency.

2. Align the design knowledge that users have accumulated through experience with other types of skill/knowledge, (e.g. service design, software development, business strategy) in collaborative networks.

3. Support positive growth and development for all stakeholders.

I undertook two prototyping cycles in response to these objective:

- A participatory storytelling group (Section 5), in which a group of people explored a variety of personal experiences of access barriers. The storytelling method that I used was created at the intersection of

organizational learning practices, the use of narrative in design and in research, and the role of first-person stories in self-emancipation and advocacy.

- Development of AccessMakers, an integrated online community and inclusive design process that engages organizations directly with stakeholders who experience access barriers (Section 6). Evaluation of these artefacts was given by five senior managers in service agencies and small and medium-sized enterprises (SMEs).

The Story Capture Technique (Section 5)

The first prototype is called the 'story capture technique', and it was developed through a participatory storytelling group in which eight people who experience access barriers took part.

Here I give a full description of how I developed a participatory storytelling method and some of the highlights of the content from the stories gathered. These give a more robust and nuanced view of what it means to experience barriers to participation or activity, and how those experiences are given meaning by the storytellers. The stories stand, on their own, as valuable data for anyone interested in issues relating to design for access.

The results also yield a 'story capture technique' that is very effective as a service design method for accessibility. It preserves the richness of lived experience but, at the same time, provides a structured dataset that can be communicated and re-used by teams of collaborators.

AccessMakers: A Platform for Inclusive Innovation (Section 6)

After evaluating the story capture technique, I created AccessMakers, a platform consisting of workshops and an online community portal that provides an inclusive approach for:

- Individuals to tell their stories and seek collaborations to resolve access barriers.

- Collaborative teams to identify and frame inclusive design challenges and generate innovative solutions that are meaningful to both individuals who experience access barriers and the other stakeholders who are necessary to make change.

Through AccessMakers, people can work together to remove barriers and, at the same time, contribute to innovation in services more generally by taking advantage of the unique insights that people with disabilities often have.

It is also an online community. This is an important dimension in which the story capture technique also functions to support the development of collaborative teams. The report illustrates the range of roles that online community members

may choose to play, using crowdsourcing and peer-production techniques as well as personal and organizational portfolios of stories to guide access design projects. Wireframes are used to highlight key points.

Concluding the Journey (Section 7)

The final section summarizes my broad conclusion that the complexity and granularity of access design *can* be encompassed by the distributed, participatory world wide web. To make full use of this amazing platform and its power to create new toolsets, we need to develop individualized networks for innovation, and support people acting as prosumers not only for their own needs but for their communities as well.

AccessMakers is designed to enable inclusive feedback loops at all levels – starting with participation for people at the social and economic margins, leading to better problem identification and adaptation of methods to be more inclusive, in turn creating better products and services that, drive greater participation for all.

In addition to reviewing the design objectives and how they were met, I also discuss the limitations that led to new learning along the way.

Readers will also find a review of how I think I have contributed to the field of inclusive design, namely filling out the design definition of disability with concrete data, prototyping the use of narrative as an inclusive design method,

and the finding that participatory methods and collaboration *are user requirement of access design* because of the co-creative nature of access experiences.

In addition to the future-oriented steps recommended for the AccessMakers platform in Section 6.4, this conclusion section offers recommendations for further research and prototyping in the areas of leadership storytelling, extension of the method to groups of users in long-term care or group homes or who may otherwise experience social barriers to collaborative networking on the web, the creation of a *pattern language* for access design, and the relationship of design practices to advocacy in a user-network like AccessMakers where some stakeholders may be unwilling to engage.

The stories and the AccessMakers modules are in the Appendices following the reference section, at the very end of this report.

John D. Willis

2. Context & Inspiration

I am a designer and a student. I am a father of two, and I have some unusual experiences every day because I have low-vision and most of the world doesn't share that with me.

This is a story about a journey that I've taken through disability and design. It traverses both my own subjective experience and that of other individuals with disabilities. Over the course of the journey, I developed a handful of intuitions into specific conclusions about the *design space of disability* and a *methodology for collaborative design* in that space.

2.1   Starting the Journey

To begin, consider two days in my life.

Table 1: Author's Personal Journal Entries, February 11/12, 2015

```
February 11/12, 2015

The kids won't be up for an hour - time to get some work
done. Learning to use Axure (app/web prototyping
software). Turns out, on my Windows 7 desktop, the very
first dialog box has a white background; too bright for
me, I cannot read the greyscale fonts. Gave up (for now).

Walked [daughter] to school.  Long way without a car, but
the school board doesn't offer accommodation because I'm
the one with a disability, not her, and Wheel-Trans
doesn't allow me to use it for this purpose.

Thought about going to the gym; remembered that all the
cardio machines were recently replaced and now have grey-
on-black controls that I cannot operate independently.
Mental note to drop membership.
```

Back home, reading time. Big stack this week. But the textbook is not available PDF/EPUB directly through OCADU. Not enough time to get the hard copy, deliver it for scanning, wait a few days… went for Kindle edition instead – sadly Kindle is a poor research platform, e.g. no page numbers (how to cite?!) and very cumbersome annotation tools. Spent so much time fussing with the software, barely remember what I read. Probably skip it anyway, as it relates to the Axure prototype – which I may have to drop from my research now anyway.

Crazy busy with work, family and MRP – put new 'to be done' list into Evernote (web). Downloaded iPhone app, but cannot read mobile interface due to very low contrast. Tweeted complaint to @evernote (no response).

Almost hit by streetcar (twice) at waterfront transit stop that I've been using for years. Apparently the stop was moved, and the whole roadway has been shifted north, but there's no signage that I can see, so I ended up in the roadway. I could tell I was in danger, but it was only the 3rd streetcar driver that noticed my white cane and stopped to tell me where to wait instead. Tweeted complaint to TTC – no response.

Evening networking event at MaRS, an update on the world of social innovation. Update on MaRS: Not a very inclusive event. No guidance to seating, coatracks, refreshments. Stumbled around for a while, ignored. Sat at the back as the front rows all blocked off for VIPs but I could find no assistance to ask for an exception - couldn't see the slides on-screen. Submitted note to organizers w/ suggestions (no response).

Next day: attended market research certification exam. Very strict timing and rules for exam. Had asked for accommodation prior, but exam questions given only on paper and computer (for answering) not set up for my situation, could neither read nor respond. Spent 40 minutes a) explaining situation to examiner; b) locating technical support; c) changing fonts etc. on computer; d) locating electronic copy of the exam questions. All done in front of 12 other students, trying to ignore the

```
disturbance; woman beside me asked to change seats, too
frustrated to continue near me. I was not given extension
of similar time to complete the exam.

Stopped at the grocery store to get bread, fish, veggies.
I don't like the bakery at this store – loads of faux-
rustic baskets of breads BUT very small labels that I
cannot read, and it is self-service so no one to ask for
assistance. Spent 10 min finding a guy two aisles away
who said 'I don't do bakery' so, I just took a guess at
what I was buying. Prefer the fish and meat counters,
where there's service.
```

This journal entry recounts nine incidents in which I encountered 'access barriers' –the combinations of design elements and my characteristics that, together, have the effect of hindering the possibilities for action (affordances) that I need to achieve my aims.

Perceptual psychologist James J. Gibson coined the term 'affordance' to denote the possibilities for action that an environment or context offers to an individual. In his usage, affordances are independent of the perception of the individual – they exist regardless of whether they are known to exist. Don Norman later re-purposed the term, in the context of product design, emphasizing instead that possibilities for action (affordances) arise from the *interaction* between the qualities of objects and the knowledge and expectations of a person using it. Norman's view of affordances incorporates a distinction between *perceived* and *real* affordances, especially in the idea that designed objects ought to communicate their possibilities for action to potential users. (Norman, 2013; McGrenere & Ho, 2000).

John D. Willis

In my journal, we can see that the grocery labels and a self-service delivery model at that bakery do not communicate effectively the possibilities for my intended action (selecting the bread that I want to buy). From a design standpoint, they fail with respect to my needs as a user. The interaction instead presents a barrier to action, as do the Axure web interface, and the functions of the mobile reading app – these are all 'counter-affordances' for my actions. On the other hand, these same designed elements are affordances for other people (or me, at other times).

These observations support a *design definition of disability* – the idea that we should treat disability as the result of a mismatch between the needs of the individual and the resource, service, or environment in which they are pursuing their goals*. (Jackl, Treviranus & Roberts, 2004). This means that *disability is a relative quality*, not an absolute, and a person with a disability is not a clearly-defined type of person. In many situations, my poor eyesight is *not* a disability – for example when I'm learning guitar from YouTube videos (my hearing is sufficient); when I'm in class at OCADU and I can log onto a network to see the lecturer's slides (I can be in the same room, or across town); or when the fishmonger at the market selects and bags my order (I only need to ask questions and formulate a preference).

Affordances in daily life are *invisible* when they are functioning up to our expectations. Digital media educator Kathy Gill notes that usable web sites are

transparent in that they 'don't make you think'. Quoting Krug (2005) Gill writes:

"When I'm looking at a page that doesn't make me think, all the thought balloons over my head say things like 'OK, there's the ____. And that's a ____. And there's the thing that I want." (Gill, 2012, section 1, para 5)

This state of 'not thinking' is an aspect of what psychologist Mihaly Csikszentmihalyi called 'flow' (2008), which he says is "the way people describe their state of mind when consciousness is harmoniously ordered, and they want to pursue whatever they are doing for its own sake." This is often called 'being in the zone' and it is usually the first thing that is undermined or destroyed by access barriers.

I conclude that these access barriers are understandable in terms of user experience, or rather, an access barrier should be termed an *access experience,* and we should adopt design approaches -- such as interaction design and service design -- that are suitable to designing for experience.

The incidents that I recount above also highlight the networked character of even a single access experience. In the grocery store, the bread and the baskets and the labels are part of a fully 'designed' user-experience that includes serving one's self. Since these affordances don't work for me, I am required to seek assistance from another human being who is not an intrinsic element of the bakery system. That individual turns out to be poorly equipped to respond to my needs; if I pushed this a step further I would perhaps have asked to speak to the

manager. Undoubtedly I would have got my bread regardless, but to resolve the access barrier so that it does not recur would require some re-design of the bakery system. The manager would need to escalate the concern to an even higher level within the organization.

At that point, we would be dealing with not just designers, but corporate decision-makers and accountants, procurement and outsourcing managers, and logistics experts. It turns out that the bakery system in my local grocery store sits within a larger system, which sits within an even larger system – all made up of people, processes, and resources in specific 'designed' configurations.

What I want is some way to connect myself to that system, have my voice heard, and my insights about what needs to be fixed valued. What would that look like? What is the right approach to valuing individual experience in a design process that, nonetheless, operates at a systemic or organizational level?

2.2   The Landscape

Every day, there are more of 'us' – people with disabilities – and my experiences of blocked activity and exclusion from participation is multiplying. Disability is growing in Canada, as it is around the world, because more of us are older, and we (on average) are living longer lives. 2015 marks the first year in which there are more Canadians over-65 than there are Canadians under 16. Disability is part of daily life for one-in-three people over-65 and one-half of those over 75 so

as our total population ages, disabilities will rise from 14% now to 18% in 2036 – a net growth in those of us with disabilities of nearly 3 million people (to 6.4m in 2036). (based on Statscan, 2014, 2013)

At the same time the working-age population will shrink by nearly 10%.

If this future is similar to the past, those new millions of people with disabilities can expect lower than average incomes and much higher rates of unemployment than other Canadians. (Stapleton, 2013; Galarneau & Radulescu, 2009) They are likely to be excluded from social participation, civic engagement, and online communities. (Melchior, et al., 2014; Chadwick, et al., 2013; Fox & Boyle, 2012) Even climate change and the level of public infrastructure have a differential effect on people with disabilities - we are thought to be subject to discrimination during disasters and disaster-relief efforts.[1]

We know that *diverse societies must be inclusive to be successful.* Diverse perspectives in organizations, in policy-making, and in civil society lead to more effective problem solving and creative responses to disruption and stress. Inclusive societies tend to be less violent, and experience lower rates of mental illness, poverty, criminal behaviour, and other collective pathologies – in part because the incorporation of 'divergent' views and experiences induce higher levels of tolerance, creativity, and innovation throughout the society. (Page, 2007; Treviranus, 2009; Wilkinson & Pickett, 2009)

---

[1] 'Disability, at https://en.wikipedia.org/wiki/Disability, accessed October 11, 2014.

John D. Willis

We need our millions of citizens with low vision, hearing, mobility and dexterity challenges or cognitive decline to continue to participate and contribute as working people, educators, investors, taxpayers, cultural leaders, and caregivers. Inclusion of an aging population will mean bringing accessibility into the foreground in every sector, public, private and personal.

2.3   Regulation, Standards, & Innovation

There are laws about making everything accessible for people with disabilities. The *Americans with Disabilities Act* (1990)[2] is among the best known, and Ontario now has a major regulatory agenda for accessibility, called the *Accessibility for Ontarians with Disabilities Act* (2005).[3]

Reflecting the fundamental human rights of people with disabilities, these laws are a positive step forward, but they are not a complete response to the prevalence of access barriers, mainly because they function through enforcement of universal design constraints that can only address minimal user requirements. For example, websites and web apps in Ontario must be readable by screen-readers (of varying specifications), but there is no regulation for mobile apps, even though mobile computing has grown dramatically and is now virtually the mainstream of 'smart' technologies in consumers' hands.

---

[2] 'Information and Technical Assistance on the Americans with Disabilities Act', at http://www.ada.gov/, accessed December 12, 2014.
[3] 'Ontario Regulation 191/11 - Integrated Accessibility Standards' at http://www.e-laws.gov.on.ca/html/regs/english/elaws_regs_110191_e.htm, accessed November 29, 2013.

By definition, regulation emphasises the feedback loop between businesses (or other 'obligated organizations'), on one hand, and the regulator on the other – meanwhile the actual 'users' of accessibility are considered inconsequential to meeting standards. (Moran, 2015)

All of this adds up to a 'checklist approach' and dissatisfaction for users. My story in Appendix A recounts my experience of being assured that a digital interface is 'accessible' although it cannot be adapted sufficiently to allow me to access anything through it. A piece of software has 'met a standard' but, to one degree or another it simply failed to perform its function of 'providing access' in a real situation. Not surprisingly, many 'obligated organizations' find it hard to define meaningful outcome measures for their investments in meeting accessibility rules, and resist the costs and confusion of complying with what many consider 'vague' standards. (Moran, 2015)

Some adaptive technologies have been relatively successful, but they are not a general response to the risks of exclusion in an aging society. The distribution of functional abilities among the general population is a 'long tail' (many differentiated segments, each with a small number of cases[4]) and they are expressed in every possible context. This 'granularity' and diversity of people's actual requirements is a major problem for vendors of specialized 'adaptive

---

[4] 'Long tail', at http://www.investopedia.com/terms/l/long-tail.asp . As a popular term in business, the 'long tail' came from Chris Anderson in 2004 and referred to markets of a large number of niche goods; it can also be defined as a time period 'in which sales of less-common products return a profit due to reduced marketing and distribution costs.'

technologies' or any other approach to inclusion based on generalizations. (Ayotte, et al, 2014; Vanderheiden, 2006) Also, adapting to technologies that are not amenable to being adapted is a key problem – for example, if a website is coded in Flash, no screen reader can interpret it, period, regardless of how well the screen reader software is designed. The barrier in that case lies in the decision to code in Flash, making the design un-adaptable by a screen reader.

So what's the alternative?

Inclusive design is a human-centred practice that addresses the shortcomings of accessibility design in the following ways:

- By understanding individuals who experience barriers as 'edge case' users rather than a discrete category such as 'disabled', inclusive design appreciates the creative importance of needs that are often treated as outliers (statistically insignificant) in traditional marketing, innovation, and design. This approach takes advantage of pervasive opportunities to benefit wider communities through innovation that is driven by these edge cases, thus creating mainstream products and services that meet the needs of people with diverse abilities.

- The use of participatory methods and co-creation with users or beneficiaries of design means going beyond 'empathy' for users and instead giving them tools and processes to be creators in their own right.

This produces more appropriate outcomes because users are collaborators rather than merely a list of 'requirements'.

- Inclusive design aims for outcomes that are adaptable and flexible, the better to meet individual user needs. The slogan 'one-size-fits-one' emphasizes customization to diverse needs, rather than a so-called universal design solution ('one-size-fits-all'). (IDRC, 2013; Treviranus, 2014)

Appreciating the challenges of complexity, Prof. Jutta Treviranus told the opening plenary of the *Designing Enabling Economies & Policies Conference* (DEEP 2014) in October 2014 that inclusion is *"…a technically-complex agenda, that is not yet fully defined, addressing thousands of moving targets, some in areas we are restricted from, across a huge disjointed terrain."*[5]

The alternative, she asserted, is to take advantage of the world wide web to build collaborative networks around the 'lived experience' of people with disabilities and create new solutions out of peer-production and crowdsourcing of knowledge from around the world. (Treviranus, 2013/2014a)

This approach is inspired by the participatory culture of the internet, especially the 'free and open-source' software movement (FOSS), and the 'peer-production' tactics of user-networks like Wikipedia. (Tapscott & Williams, 2007; Kelly, 2005)

---

[5] Author's notes, October 16, 2014.

John D. Willis

The world wide web provides adaptable and flexible tools for users to play a major role in their own innovations, enabling 'one size fits one' solutions rather than 'universals'. This way of thinking treats the individual with an access experience as a potential 'edge case' whose perspective reveals opportunities to rethink and redesign the affordances of the containing system, organization, culture, product, or service. In this perspective, the diversity of user needs is a positive feature of the 'ecosystem', increasing creativity and yielding innovations that have benefits beyond the individual user (the so-called 'curb cut effect')[6]. (Treviranus, 2014; IDRC, 2013)

Unlike regulations or highly-specialized technology solutions, this approach to designing for access puts more stock in *an inclusive process for innovation t*hat could be self-sustaining, rather than trying to define specific outcomes *a priori*. By emphasizing process and practice over outcomes and products, we can move toward greater inclusion at scale, *without losing responsiveness to the sheer diversity of access needs*.

So how do we apply inclusive design to access barriers in real life? What is required is an approach to designing for access that works *at scale*, but that can

---

[6] Examples that have been cited of the 'curb cut effect' include the telephone (inspired by A. G. Bell's affinity to his local deaf community), the typewriter (invented in 1808 to help a blind Countess write legibly); more recent innovations such as flatbed scanners, optical character recognition (OCR), and semantic HTML have large-scale impacts beyond those whose needs inspired their creation

also be adapted and *embedded into the logic of commercial and public entities of*

all kinds.

John D. Willis

3. New Frames to Design for Access

When I started this journey (page 13, above) I said that access is a type of 'user experience', and that the general theory of affordances can help us conceive it as a space for design in which the 'users' experience barriers to their aims and activities, within a networked milieu of many stakeholders, interfaces, and processes.

There are three large-scale trends that, in combination, seem to provide a major opportunity to rethink how we create accessibility and make a more inclusive society. These are:

Economic and civic co-creation: There is a growing recognition in many sectors that 'value' – whether it is commercial or civic – is co-created by all of the actors involved (rather than being created by a 'producer' and then transferred to a 'consumer'). This 'service logic' foregrounds customer experience in many different ways and helps us contextualize accessibility as an integral dimension of all exchange.

Open innovation: New processes for bringing knowledge and insight from 'outside' of organizations into the production process are being developed for large and small enterprises, government agencies and public services – opening the door to making people with disabilities drivers of innovation at larger and larger scales.

The ICT opportunity: The world wide web offers technology and tools to put service co-creation into action between individuals, organizations of all kinds, and public service providers.

In the next section I will bring these dimensions together as a frame for setting design objectives specifically for access design in online and offline user-networks.

3.1 Economic & Civic Co-creation

Access experiences are a result of affordances that arise, or don't arise, in concrete interactions, rather than a discrete, *a priori* 'feature' of things and spaces. This perspective on disability and accessibility is strongly reflected in an influential 2004 article about the evolution of marketing by Stephen Vargo and Robert Lusch. (Vargo & Lusch, 2004) They advanced the view that services (not goods) are the dominant element of all economic exchange in the post-industrial age. Unlike traditional goods, the 'means of production' for services is 'co-creation' by consumers and firms, at the intersection of:

- Tangible resources - facilities, materials, and labour time

- Intangible resources - skill, know-how, and opportunity

- Customers' desires and needs, also time, funds, possessions, facilities

In this view, the customer is always a co-creator of value and determines what is valuable in the exchange relationship. (Vargo & Lusch, 2004; Vargo et al., 2008) Natalie Lehoux, a researcher at Bell Labs, describes services as exchanges that are 'enacted' rather than 'provided'. (Lehoux, 2013) Starting in the 1970s and 80s, the co-created nature of public services was remarked on in Chicago (police need the community as much as the community needs police) and the UK (doctors need patients as much as patients need doctors). There are now many deliberate efforts to mobilize citizens for the purpose of 'co-creating' public services in mental health and other types of healthcare, social services and transport.[7,8]

In services exchanges (e.g. we subscribe to a streaming music service instead of buying a physical LP or CD), what we consider to be the value of the exchange comes to us through the *experiences* that we have of that service. Physical products are, more and more, simply vehicles for what service designers Helkulla, Kelleher & Pihlstrom call 'value-in-experience'. (Helkulla, et al., 2012; Vargo, et al., 2008) Interfaces and product functions recede into the background, or become more transparent, as we focus our desires on intangible experiences. (Brown, 2005)

---

[7] New Economics Foundation, 'Co-production', http://www.neweconomics.org/publications/entry/co-production, accessed March 10, 2014.

[8] It was in the public service context that the term 'producer-consumer' (later, 'prosumer') was coined to describe those who "produce services in order to consume the resulting output" (Brudney & England, 1983, quoting Kiser & Percy, 1980).

John D. Willis

A very important design and inclusion implication of this is that *all of the many factors that affect customers are intrinsic to the production process*, including feelings, expectations, physical abilities, and memories. Elements of social meaning – religious beliefs, prejudice, misinformation – were traditionally assumed to be 'outside' the production process but are also now understood as part-and-parcel of how value is created between people and organizations. Claudio Pinhanez evocatively notes that in service systems "the customer is on the conveyor belt," and defines the relationship as one in which the customer is necessary to the means of production and yet remains autonomous of it. The challenge of contemporary service systems design, he says, is to avoid dehumanization in technological architectures and processes. (Pinhanez, 2012, pg. 7)

Through this lens, accessibility is on a continuum with usability in general. Since all customers and citizens need access to the diverse flow of value-in-experience that makes up our economy, a person with a disability is not different than the mainstream, but rather someone whose edge case experiences can reveal weaknesses in system design, and spur innovations that benefit a much larger community of consumers or citizens.

This suggests that service design, and the emerging field of 'service science', should be fruitful for designing for access.

According to Evenson and Dubberly (2010), designing services is a 'meta activity' of "conceiving and iteratively planning and constructing a service system or architecture to deliver resources that choreograph an experience that others design." (2010, pg. 2) Users have distinct and often unique characteristics, however, so the design of each experience within a system architecture may be unique.

3.2   Open Innovation

To the extent that value is co-created with customers and they alone determine what is valuable through their own experience, the design challenge is not so much creating great experiences as it is *to give customers (or citizens) the tools to design their own experiences.* (Evenson & Dubberly, 2010)

This phenomenon manifests in many ways: in consumer products, 'mass customization' is common; in healthcare and other complex human services, 'human-centred design' (HCD) takes a leading role; in service delivery *per se*, innovators now seek 'real-time interaction management' and embed 'data-driving' technology into everyday appliances. On the web, crowdsourcing and peer-production engage millions of people in the so-called 'sharing economy' that disrupts traditional enterprise as well as labour markets.

I use the term *user networks* to describe the unification of the types of open innovation reviewed here, around the needs of people with disabilities.

- **Open innovation** ('outside-in') happens when companies bring the knowledge or effort of consumers (or any external actor) into the production process to drive innovation. (Gassmann, et al., 2010; Chesbrough, 2006) This practice grew out of the high tech and software industries, related to technology R&D and product design. More recently, consumer products have been subjected to so-called open innovation processes. (Gassman, 2010; Pillar, 2004)

- **User innovation networks** (also called 'horizontal' innovation) refers to peer production between individual users without the need for authorization or resources of a company or agency. (von Hippel, 2007) For my purposes, this includes 'maker' communities, both offline and online.

Bringing the 'outside' in, is also a growing theme in the public sector, where the complexity of contemporary policy challenges are seen as unresolvable without greater collaboration with citizens in general and service users in particular. (Wise, et al., 2012; Gold & Hjartarson, 2012; Holmes & Brenton, 2011; Brudney & England, 1983)

A key reason for creating these innovation platforms is that knowledge often exists in a different location within a system, or beyond the system boundary, relative to where innovation processes take place (Enkel, et al., 2009). This is

precisely the challenge of designing for access in the sense that there are

multiple and diverse experiences widely distributed but not integrated with

other resources for innovation. Shifting innovation into users' hands is, in part, a

matter of giving them the tools to gather up the context-dependent knowledge

they already possess and bring it into alignment with a firm's or organization's

innovation process. (von Hippel & Katz, 2002) In other words, users need to be

empowered to design not just their own experiences, but the architectures and

processes of service systems, through collaboration with firms, organizations,

and agencies that control or have authority over those systems.

The relationships are represented in Figure 3, below. In the first instance (1), a

user who encounters a barrier seeks to (re-)design their experience through the

tools provided in the service architecture; in the second instance, (2) a user may

seek to engage stakeholders who have capacity to change the architecture itself,

by managing, or disrupting, the system.
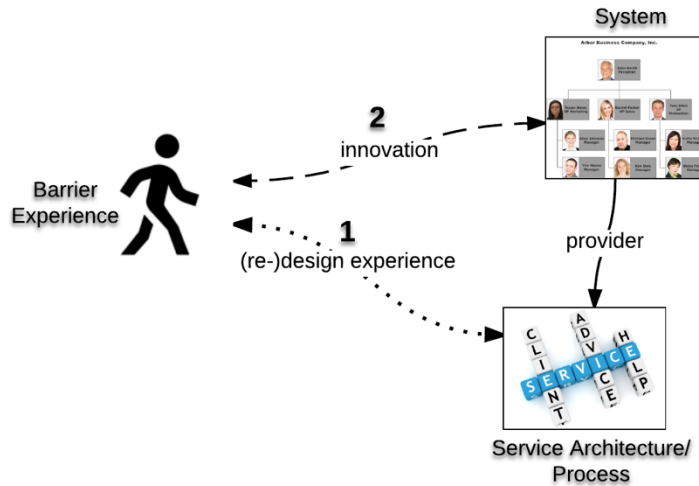
Figure 3: Relationship of Collaborative Design to System Innovation in Access Experiences

My transit system experience of almost being run over by two streetcars (pg. 13) demonstrates the extent to which I, the user, am required to 'design' my own experience within the (rather dangerous) 'architecture' provided by the system. But it also highlights the extent to which other actors in that co-creative process are not engaged in a user-centred innovation process, do not have a user-network to bring the outside in, and do not have processes in place to gather up the context-dependent, lived experience that I have to offer. The breakdown of affordances that I, and other people with disabilities, experience in various service systems are very clear to us but not necessarily to those who have skills, authority and tangible resources to apply to them (as shown by the stories in the collection in Appendix A).

3.3   The ICT Opportunity

The most important tool of all for supporting users and citizens to create their own access experiences is the world wide web. (Treviranus, 2014; ITU, 2013; Tapscot & Williams, 2007; Kelly, 2005) It has arrived just in time to give more 'control' (variously understood) to user, citizens or consumers who co-create the services that they also consume. The internet is also clearly a public infrastructure available to all for innovation in services and products.

The pervasiveness of open source ICT is exemplified in the so- *maker movement*, which has been described as 'a nation of innovation hobbyists working to make their lives more meaningful and the world a better place.'[9] Sharing software code was the mark of the *free and open source software' movement* (FOSS) but now individual creators are sharing all types of 'maker' knowledge including patterns, 3D printing and computer-aided design (CAD) files, digital instruction sets for all types of machinery, and engineering specifications for robots that can reproduce themselves. (Budhathoki & Haythornthwaite, 2013; Lakhani & von Hippel, 2003)

Examples of this form include **openprosthetics.org** (customized, low-cost prosthetics created in a peer-to-peer network), **Amara.org** (captioning/subtitling of videos on the web via crowdsourcing); **tyze.org**, a

---

[9] Mark Hatch, author of *The Maker Movement Manifesto* (pub), quoted in GoodReads http://www.goodreads.com/book/show/17718187-the-maker-movement-manifesto, accessed 17/3/15.

community of people with intellectual disabilities and their families/caregivers, set up to provide networked, personalized lifetime support; **SeeClickFix.org**, an 'alert board' for citizens to notify city officials of potholes and graffiti, and for notices of action taken to be given back to local citizens.

These concepts are being developed into practical applications on a large scale already. The **OmniAgora** is a business platform being developed in Ontario, Canada that developers describe as 'a marketplace for inclusive services and products' for three stakeholder groups: producers and suppliers that face barriers to employment and market entry; those who are under-served by current offerings; and organizations obligated by law or policy to provide accessible products and/or services. It is intended to create income, jobs and learning outcomes as well as lowering the costs of accessible products and services, in what the project's funding proposal calls 'a system of service entrepreneurship'. [10]

Could real-time access barriers be the next frontier for web-enabled user-networks?

---

[10] Personal communication, Kevin Stolarick, March 15, 2015.

4. Design Objectives & Methods

The larger social and economic trends reviewed above can be game-changing for people with disabilities. In an aging society, accessibility can be contextualized on a spectrum with all other modes of exchange of value for customers and citizens (rather than a 'special need'); the tools for co-production, open innovation, and user-networks; and many actors have grown accustomed to the practices and rewards of collaborative design and development in personal life, organizations, and the public realm.

To have the greatest possible impact, collaborative design for access should be capable of scaling up while retaining the personal agency of individuals whose experience lies at the heart of access barriers, and be adaptable for the specific needs of stakeholders in various contexts, organizations, and networks of actors.

Given the primacy of experience in service-logic generally, and access barriers in particular, there is a need to mobilize what von Hippel and Katz (2002) called the 'sticky' knowledge (context-dependent lived experience) from users, so that it can fuel innovation. My initial design focus turned to this problem, which I characterized as the collection and communication of user requirements for collaborative access design.

Oehlberg et al. (2011) model this as a 3-step process of (1) capturing users' knowledge, (2) reflecting upon it, and (3) sharing it among teams of designers. I

have annotated and modified their model (adding 'act' to incorporate the idea of actual 'production' of new access services).

Compare & Contrast,
Grouping,
Theme-finding
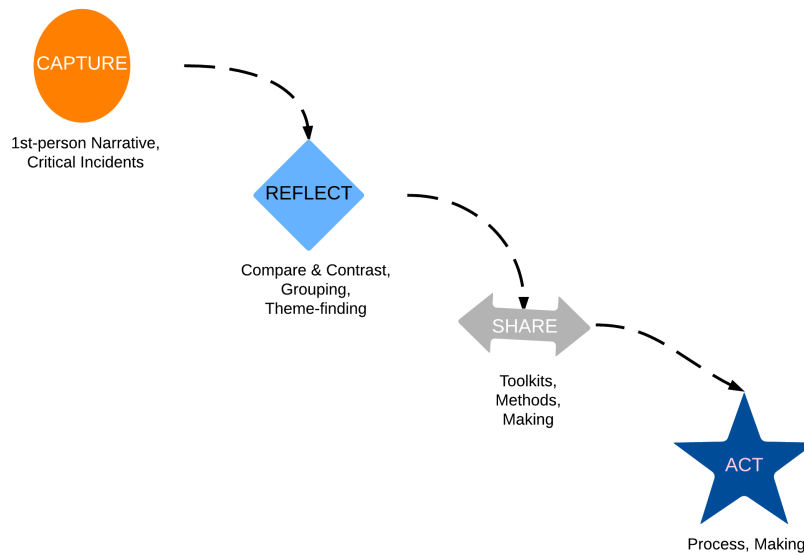
Figure 4: Idealized User Requirements Flow in Collaborative Design

The challenge here is how to create a process for users to 'capture-reflect-share-act' in collaborative networks, in a way that:

- Mobilizes and aggregates users' 'sticky' knowledge (lived experience) of the affordances and service architectures that give rise to access barrier experiences (and support service system design in general)

- Supports collaborations in networks of organizational as well as individual actors

- Supports collaborations offline or online

- Is truly inclusive for people with disabilities, positioning them as user-collaborators rather than (as often occurs) abstract 'end users' or passive consumers

- Encourages innovations that benefit diverse needs and/or stakeholders.

I undertook two prototyping cycles in response to these objectives:

- A participatory storytelling group (Section 5, pg. 41), in which a group of people recounted and explored personal experiences of access barriers. The intention was to test and refine a technique for capturing lived experience and mobilizing it in collaborative networks, without losing the individual agency of the individual storyteller.

- Development of 'AccessMakers', an integrated online community and inclusive design process that engages organizations directly with stakeholders who experience access barriers (Section 6). Evaluation of these artefacts was given by five senior managers in service agencies and SMEs.

John D. Willis

These design processes revealed many concrete dimensions of how to create

user-networks for access design. These are discussed in the following sections.

5. The Story Capture Technique

My experiences of access barriers led me to think that storytelling could be an important way to capture these experiences. Stories are a type of 'fabric' woven out of information. They 'connect the dots' between events, sequences, and characters.[11] They make information that is otherwise part of my interior life accessible to other people.

From a design standpoint, it occurred to me that storytelling seems to sit in an ideal location 'between' ethnography, on one hand, and more 'reductive' techniques such as personas, on the other. First-person stories have an extraordinary ratio of information to volume, and are capable of transmitting both facts *and* emotion embedded in a specific context. Hugh Dubberly writes that "telling stories builds a model of actors in their relationships in the mind of the listener." (Dubberly, 2008, pg. 31)

First-person narratives can be very action-oriented but also carry us into the subjective experience of the teller. A story is "a description of what happens to a person, and how they respond to it," says Sharon Williams-Ng (2012), citing this tale: "*The Queen died. Then the King died – of grief."* For designers it is invaluable to crystallize the 'whole person' – their goals and feelings, their memories and

---

[11] 'Storytelling Theory and Practice', Brian Strum, https://www.youtube.com/watch?v=UFC-URW6wkU, accessed December 11, 2014.

self-identity – rather than narrowing our attention too early to their interactions with interfaces or functions of products.

5.1   Narrative & Storytelling Today

Storytelling is a popular topic and concept in many contexts, including social research (Bold, 2012; Chambers, 2003), market research[12] and branding, (Gorry & Westbrook, 2011), executive leadership (Denning, 2011a/b) and many fields of design.

I am concerned here with two dimensions of first-person narrative that can sometimes be in tension with each other: First, as a means for individual self-expression and empowerment, and second as a design research technique. People with disabilities have, at various points in history, been dehumanized by researchers – including some with good intentions – and these tensions are not eliminated simply by labeling a process 'collaborative' or 'human-centred'. ([ref] from INCD research course)

People who have been marginalized sometimes have stories that have been bought at significant cost in pain, loss, or victimization. The telling of their own stories can have a powerful cathartic effect and has been widely recognized as a step toward emancipation for African-Americans, women and girls, people with

---

[12] 'MRIA NATIONAL CONFERENCE 2015: Storytelling: From Insights to Impact', at http://mria-arim.ca/events-awards/national-conference, accessed April 4, 2015.

developmental disabilities, psychiatric survivors, and many other groups. (Costa, et al., 2012; Hughes & Brennan, 2010). **Stories for Change**, a prominent 'digital storytelling' site promotes storytelling to "surface knowledge and leadership… build community… [and] create conditions for change."[13] **1000 Voices** invites people with disabilities to share their life experiences with video, photos, audio and text. The purpose is to raise community awareness and to "make sure that your voices become part of ongoing research, service, and policy development".[14]

However, concerns have been raised about exploitation of the narratives of vulnerable people by institutional actors with ulterior motives -- such as demonstrating efficacy to political leaders or raising money. These agendas, it is argued, diminish the agency of individuals who have the lived experience by 'cherry-picking' those narratives that support institutional goals, and leaving other, more problematic narratives, in the shadows. (Costa, et al, 2012)

One response is the creation of a 'Bill of Rights' for digital storytelling.[15] Another is the 'repositioning' of storytellers into the role of curators and artistic or scholarly contributors, as in **Out from Under, Disability History and Things to Remember**, a virtual museum dedicated to the legacy of resistance on the part

---

[13] http://storiesforchange.net/about_digital_storytelling, accessed December 12, 2014.
[14] http://1000voices.edu.au/about-us
[15] 'Digital Storyteller's Bill of Rights', at http://storycenter.org/ethical-practice/, accessed March 11, 2015.

people with disabilities.[16] Another example is the role being played by Lucy

Costa and other psychiatric survivors, in defining a new 'discipline' – 'mad

studies' – for and about the lived experience of being in the mental health

system.[17]

This type of empowerment narrative builds community capacity for action, as

opposed to 'disclosing' or displaying one's experience to increase empathy

among mainstream populations, or provide what Costa et al. (2012) refer to as

'relief' for others' need to experience trauma vicariously.

This is the claim of many contemporary advocates, including **350.org**, the

international youth climate movement. Its storytelling methodology is founded

on a syllogism: "Each of us has a compelling story to tell", and "storytelling is a

practice of leadership"; therefore each of us is a potential leader for our

community.[18]

In interaction and service design, personas and storyboards (borrowed from

cinema) are simplifications of narrative techniques that have been common in

design studios since at least the early 1980s. A persona is "an archetype of a user

---

[16] 'Out from Under', http://www.ryerson.ca/ofu/, accessed January21, 2015.
[17] 'Mad about "mad" rights', Canadian Lawyer Magazine at
http://www.canadianlawyermag.com/5020/Mad-about-mad-rights.html, accessed March
11, 2015.
[18] 'Organizing', by Marshall Ganz, at
http://isites.harvard.edu/icb/icb.do?keyword=k2139&pageid=icb.page12185, accessed
October 30, 2014. 'Toolkit Overview', by 350.org, at
http://workshops.350.org/toolkit/start/, accessed October 30, 2014.

that is given a name and a face, and it is carefully described in terms of needs,

goals, and tasks." (Blomqvist & Arvola, 2002, pg. 197) Sometimes many are

created for a single project, forming a 'cast of characters' to which a design team

can refer and design for. Scenarios and 'use cases' are action-sequences based on

the needs and intentions of personas or actual users,[19] while design narratives

are often used to capture user reactions to prototypes.[20]

The use of these tools in practical situations has been criticized for a variety of

reasons, chiefly that they are often derived from designers' assumptions rather

than empirical research. (Kankainen, et al., 2012; Blomqvist & Arvola, 2002)[21]

Design consultant Steve Portigal claims that the use of these tools reflects a clear

power dynamic: *"Personas are misused to maintain a 'safe' distance from the*

people we design for, manifesting contempt over understanding, and creating the

facade of user-centeredness while merely reinforcing who we want to be designing

for and selling to." (Portigal, 2008, pg. 2)

---

[19] As examples,
http://wiki.fluidproject.org/display/fluid/%28PGA%29+First+Discovery+Use+Case+Scenarios, accessed October 15, 2014.
[20] 'The Learning Design Grid', by Yishi Mor (blog), at http://www.ld-grid.org/resources/representations-and-languages/design-narratives, accessed April 11, 2015

[21] For an uncritical overview of these tools, see 'An Introduction to Personas and How to Create Them' at http://www.steptwo.com.au/papers/kmc_personas/.

5.2   Story creation method

My first attempt to resolve these tensions was a spiral (figure 3) in which I depicted a pathway from autobiography (story about myself), to biography (story about an individual, objectifying myself or another), and then to 'fiction' (stories about the
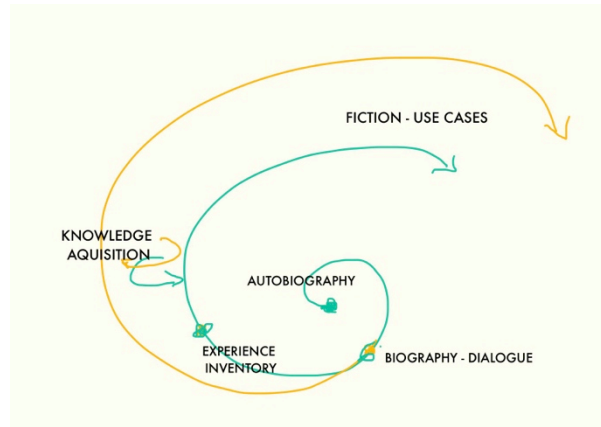
Figure 5: Concept Map, Storytelling Technique

world and ourselves, but not bound by literal details). In this I was combining Christine Bold's suggestion of three ways to investigate the world (autobiography, biography, 'representative constructions') (2011), which I saw reflected in Marshall Ganz' activist storytelling triad ('Self-Us-Now').[22]

The text labeling over the spiral shows how I conceived this pathway of storytelling would intersect with functional needs of a knowledge sharing and innovation network (e.g. by turning fictional narratives into 'use cases').

I also built on Forlizzi and Battarbee's (2004) distinction between *an experience* (such as almost being run over by a streetcar) and Csikszentmihalyi's *flow*,

---

[22] 'Telling Your Story, Marshall Ganz, at http://www.wholecommunities.org/pdf/Public%20Story%20Worksheet07Ganz.pdf, accessed March 21, 2015.

which they simply call *experience*. An experience can be recounted (from the past, in memory) or anticipated (in the future, in imagination); a story is a technique for 'pulling out' an experience and fusing the threads of meaning as they emerge from the flow of interior life.

A core assumption of the approach that I adopted is that understanding service design challenges require engaging a 'holistic' experience of the user and not only the intended relationship between a user and specific functions of a given product or service. I strongly concur with Kainkainen, et al. (2012) in their observations that storytelling is, *inter alia*, a way to develop this holistic vantage point (what they call the style of a service offering or service experience). I intended that the technique should provide the breadth of data that is normally part of a service experience including expectations and assumptions, (past and future), a sequence of events (lived experience), as well as what happened to the person as a result of the experience (which may entail imaginary events, wishes, fears about the future). Finally, by describing a scenario or action sequence, we learn about social versus individual phenomena. (Helkkula & Pihlstrom, 2010)

Finally, *The Liberating Structures Menu*[23] by McCandless & Lipmanowicz was a strong influence on the practical setup and 'tone' with which these workshops were delivered, especially their emphasis on ensuring that each voice in the group is heard.

---

[23] 'The Liberating Structures Menu', www.liberatingstructures.com, accessed October 1, 2014.

John D. Willis

I developed the technique through two iterations of a participatory storytelling workshop (held in Toronto on October 31st with 3 participants and November 12 with 4 different participants). The actual technique was deployed as follows:

First, the facilitator/lead researcher gave a 5 minute 'lightning talk' about the idea of 'curb cuts' – innovations that arise from unique lived disability experience of people with disabilities, but which have wider benefits. Reference was made to the blind Countess Carolina Fantoni da Fivizzano and [the invention of an early typewriter in 1808, a popular example of a curb cut.](#) This was intended as a way to highlight and frame the fact that each of us has unique knowledge that may be very valuable for innovation and design of new services or products.

Based on the '1-2-4-ALL' technique as outlined in *Liberating Structures,* participants were asked to:

> Reflect **on their own experiences when they have felt they could not gain access to a product, or service, or environment, or process due to a functional limitation;**

> Recount **one story of based on real experience, with a partner in the group; each person in this setting was asked to listen well enough to the other's story to be able to recount it, and specifically:**

WHAT HAPPENED – the events, in sequence

WHO WAS INVOLVED – the characters in the story

WHERE IT HAPPENED – the setting of the story

WHAT GOAL or PURPOSE the protagonist was pursuing when they encountered the access issue, and

THE FEELINGS that arose – for any of the characters – in the story.

Share stories in a small group (the intention was to combine two sets of partners to create groups of four, however, with support people/colleagues the numbers were uneven). In this context, participants were asked to visualize the elements, or episodes, in the story. Large sheets of paper and drawing pens were provided and an 'example storyboard' was shown by the facilitator.

Pinpoint: **Each individual storyteller was then asked to identify within their story a 'critical incident' – defined as that part of the story, or moment, that has the most explanatory power for communicating the meaning of the story to others. For example, I provided the group with my own critical incident as follows: "I explained that the new system made it almost impossible for me to read my computer screen and he said 'oh, it it's accessible, but I**

guess it just doesn't work for you'. My problem, in other words."

(See Appendix A)

I nested a version of *critical incident technique* (CIT, a method borrowed from web user testing), nested within the overall storytelling process, to encourage the storytellers to use concrete imagery, metaphors, and descriptions. Following Helkkula and Pihlstrom (2010), I hoped to surface unique experiences that would complement the service context – which may be common to more than one storyteller - contained in the narrative (see 'Pinpoint'-ing step, above).

Regarding the process of having listeners 'require' a certain structure from the storyteller, this ensures that the data furnishes insight at the next stage of analysis without compromising the authenticity of the teller's intent. (Bold, 2011)

There is a similar caveat with respect to whether storytellers' recollections are strictly 'true'- they were asked to tell a story of an experience that actually happened to them; however the tellers' feelings and attitudes to the experience that are occurring in the present, as they tell the story, are justifiably part of the dataset even though they did not take place concurrently with the events in the story. I think this demonstrates the way that a narrative is a 'linking thread' (Kankainen, et al., 2012) connecting the various elements of experiences that take place simultaneously in memory, the present moment, and imagination. To rule these data out of order would, in my view, unnecessarily diminish the impact of the story technique.

5.3   Follow-up Dialogue and Second Workshop

Participants were invited to reflect on their stories and discuss possible solutions to access barriers, in an online (Wordpress) dialogue that followed the first workshop. (See Screenshots at Appendix B.) There was very little activity in this mode of dialogue, with only two respondents participating over a period of 10 weeks, during which I (as lead researcher) tried to prompt discussion on a variety of specific topics and by e.g. posting sketched journey maps and asking tellers to discuss their relevance.

In a second workshop on January 31, 2015 (in which five of the original eight storytellers took part) participants were given the opportunity to reflect on their experience of telling their stories, and asked to discuss if it had altered any of their perceptions or thoughts. (Protocol at Appendix B) They were also asked to use sketches or diagrams or text description to imagine alternative future scenarios in which the access barriers were resolved. Each individual was given an opportunity to share their ideas, and then the group also shared about each person's story.

Figure 6: Screenshot: Journeymap in the Online Dialogue

John D. Willis

Like the online dialogue, the storytellers present at the January 31st workshop had little inclination to shift out of a 'reflective dialogue' in which they shared a flow of common knowledge and ideas, to a more 'dialectical' one in which they might have identified and sought to productively resolve oppositions arising in the stories (as a designer might do). (Isaacs, 2008)

The second workshop was, in my view, far more a 'focus group' of deep exploration around common issues of disability and accessibility, than a design studio, despite my efforts to create conditions for the latter. This was a significant finding of the participatory method for this project and spurred the creation of the second prototype (next main section).

5.4   The Stories and Storytellers[24]

The story workshops involved eight people with disabilities including:

- Tom told a story about losing a valued job due to episodic mental health circumstances.

- Sharon told a story about trying to get a taxi to a meeting but being told by the driver that he would not take a service dog.

---

[24] All of the stories captured for this project are contained in Appendix A.

- Graham, a student who was not accommodated for an exam in computer programming, causing him to fail his course.

- John (author of this report) told a story about losing access to professional work when an employer did not accommodate adaptive software for low-vision; he also told of an unreadable restaurant menu.

- Adele, a Montrealer, told about how she set out to pay her own way through school but was stymied by a workplace lacking appropriate software for her needs.

- Stephanie spoke about losing touch with one's community of friends because accessible housing was not available.

- April, an actor and dancer, talked about losing career networking opportunities due to insufficient signage about accessible entrances into a venue.

- Kazue, a young professional woman, described losing her way in downtown streets and how she was treated by passers-by.

(Storytellers' names have been changed to preserve their anonymity.)

These stories illuminate both the *content of access experiences* and the ways in which these experiences *can be mobilized* in collaborative design processes (see next two sections). On the other hand, the process was not successful in creating

conditions for the storytellers themselves to undertake steps toward design solutions – some possible reasons for this are discussed in the Evaluation, starting on page **Error! Bookmark not defined.**.

5.5   Access Experiences

These stories strongly confirm the validity of the 'design definition of disability' and, in my view, that the design space of disability is that of service systems (as defined above).

> **Breakdown and inertia:** Access barriers frequently occur when the teller's physical or other limitations encounter inertia in the service system - lack of knowledge by others (John's, April's, and Graham's stories), long time lags (Stephanie's story), lack of concern by others (Sharon, Graham, John, April). These points highlight the importance of knowledge and information flows within an access system. (See Appendix C)

> **Social experience:** All of the stories captured in this project exhibit a strong social dimension in the teller's experience. There are many people involved in an access barrier, and access barrier experiences are often 'co-experiences' in the sense that they are not possible without the engagement of other people. A very notable feature of some stories (e.g. Sharon, April, Kazue) is the teller's sense of being 'looked at' – perhaps

this is an interaction category to be added to the triadic formula of 'experience/an experience/co-experience'? (Forlizzi & Battarbee, 2004)

Aims over interfaces: What people want access **to** are the same goals or tasks that everyone pursues at one time or another: Doing their best on-the-job (Tom, John, Adele), making choices about learning new skills (Graham, Kazue), earning an income to take the burden off parents (Adele), and participating with others in professional or social life (April). In this sense, accessibility will involve the design of interfaces, but its purpose is to restore the sense of 'flow' between a person and whatever they want to do with their life. If that flow is not restored, the result is that individuals are encouraged to abandon their aims altogether. Graham wasn't allowed to take his university exam on computer, so he failed a course in which he'd been successful. This simple lack of an accommodation harmed his career. He noted in discussion that some mentors recommended he abandon his chosen career path due to disability – an exclusion that has historically been very common for people with disabilities.

Emotion: People experience very strong emotions when these events happen, including anger, a sense of betrayal, and diminished expectations for their future ability to remain independent. "Maybe I won't ever be able to hold a job", said Tom. Storytellers frequently expressed regret that they did not act differently in the moment, and wishes or fears about

their personal futures, usually linked to very strong memories of how
they felt during their experience. This points to the power of the
narrative technique to surface the multiple dimensions of experience -
but also raises a cautionary flag for researchers about the importance of
creating safe spaces for storytellers in collaborative teams.

In reflection on their experience of telling the stories, participants developed a
number of important themes that can inform collaborative design for access:

'Shadow work' and self-accommodation: Access barriers mean that the
person experiencing them often must create a 'work around', that is, an on-the-
spot accommodation for themselves. Two participants called this 'shadow work'
– tasks not shared by others who don't notice the breakdown of affordances in a
situation.

But work-arounds cause fatigue, and sometimes one does not know how to self-
accommodate, so often this path leads to self-exclusion. Kazuo told us she
doesn't attend many career- and job-oriented networking events because they
require travelling at night. I shared that my loss of sight caused me to self-
exclude from many career opportunities throughout my late 20s and early 30s. A
key point for designers is that self-exclusion is invisible at the system level – the
user simply doesn't show up at all.

Needs vs Effective Needs: When a person experiencing an access barrier is accommodated either by their own action or assistance from others on-the-spot, this may meet their immediate but *minimal* needs. What people need are seamless solutions that enable them to be productive and independent (what human factors specialists call 'effective need').[25] For example, Adele's tale of propping up her keyboard and putting her nose to the monitor to read her script was only feasible for a couple of weeks and, as her productivity fell, she was let go. Her 'effective need' was to access and manipulate digital information at-will (like everyone else).

'Secret Knowledge': Being able to perceive the possibilities for action is as important as the underlying existence of those possibilities. (McGrenere & Ho, 2000, distinguish affordances from the perceptual information about them). It's often assumed people who experience access barriers must have special knowledge of how to resolve them – where to find accessible housing (Stephanie), or the ramped-entrance hidden in a building (April), or how to make software work on every platform (John, Adele). This is often the case – and is valuable context-dependent information in a collaborative design context. But this assumption is an added burden, a 'secondary disability' because it often

---

[25] Personal communication with Greg Vanderheiden, February 14, 2015.

means that others can excuse themselves from knowing how to accommodate people with disabilities.

Complaints and Feedback: In most of the stories for this project, there are identifiable actors that could, in theory, help to resolve the access barriers in question – a restaurant manager/owner (April), a call-centre or other employer (Tom, John, Adele), an academic department (Graham). However the feedback mechanisms to these actors is often weak, rigid, or non-existent (note my journal entries in which I gave digital feedback to three organizations without any response from any of them). Storytellers spoke of 'whining' and 'complaining' as a role they feel they have to play sometimes to get attention to their needs.

Overall, these stories highlight a preferred future in which one is:

- secure and safe, not vulnerable, not 'looked at' (Sharon, April)

- able to participate in the flow of things-not-planned-for (social experiences) (Stephanie, April, Kazuo)

- able to perform up to one's own highest standard (Graham, April, Kazuo, John)

- not positioned as an 'unusual' case needing 'special care'.

5.6   The Use of Narrative in Design Process[26]

Structural analysis demonstrates that this method generates rich data that can

be structured and analyzed in a number of ways. I generated a structural

analysis that was suitable to understand each of these stories in comparison to

all others, with these categories (see page 112): self-identity, goals and

aspirations, places and things, sequences of events, people, feelings, and wishes

(or fears). These categories appeared in every story in the first workshop, and

two further categories were developed – though with less richness and nuance,

for reasons reviewed in Sections 5.7 and 5.8 - in the subsequent dialogues:

possible solutions to barriers, and what I came to call 'new futures' (more

concrete narratives based around the tellers' wishes and fears). The quotes in

the table at Appendix C are selected to be representative of the category they are

associated with.

The story data can be categorized differently, of course, depending on the needs

of the user-collaboration team that is working with them. A simple example is

that the table I created on page 112 could just as easily use headings taken from

Helkkula et al. (2012), namely: past vs future, social vs individual experience,

and lived vs imaginary experiences. Or they can be re-arranged for use in design

methods such as use cases (by focusing on sequences, places, people), personas

(grouping data about tellers' self-identity, aims, and feelings), or projective

techniques for imagining new service offerings (taking cues from the way

[26] The tools and table mentioned in this section are found at Appendix C, page 59.

storytellers use metaphor, humour, feelings, and wishes about the future). In appendix C I also show two possible ways to communicate and use the story data in service design – an action sequence based on Sharon's story, and a quad chart containing information taken from the story structure analysis mentioned above.

Through the use of community tagging, stories can also be enriched by the storyteller, by the circle of storytellers, or by other team members to include information about design domains that are implicated, specific technologies, code, or processes that are known to offer solutions, names of companies or other stakeholders that the original teller may not have knowledge of. This is an option that I discuss more in Section 6.5 in the context of how AccessMakers can become an online community. This approach is particularly exciting as it has been shown in other contexts, for example in crowdsourcing accessible streetmaps, to be a powerful method for group creativity across distances and difference of culture, skill, or levels of knowledge.

However, rather than encouraging collaborative teams to sort and resort raw data at will, it would be important to establish community norms that stories should be transmitted whole to preserve fidelity in the original lived experience, and thereby, the individual agency of tellers. This would be especially important in an online context, where different user-networks could be accessing the same datasets according to their needs.

One dimension of the data that I have not mentioned yet is the use of *humour*

and Metaphor in the stories. Storytellers frequently deployed imagery,

metaphor and analogies to make their points clearer or to engage the listeners.

Tom's story features a speeding police car and an imagined cadaver (which

thankfully did not materialize); Graham invoked physicist Stephen Hawking,

who is a man who uses a wheelchair and communicates using a speech-

generating device, to highlight the level of ignorance shown by his own course

instructor. Stephanie underlined her feelings of isolation and regret with a

reference to Santa Claus, whose annual parade in Toronto she would not witness

with the 'carpe diem' spontaneity she had imagined when she moved to the city.

5.7 The Storytelling Experience

In the second workshop, participants were asked if the experience of telling their stories had raised new thoughts or altered their perceptions in any way. Most of the five gathered for that workshop expressed very positive views and feelings – one said that the experience had brought him 'back to the right focus' in his professional life, and another said that the experience had been a positive reinforcement to her sense of self-esteem.

As noted below in the evaluation section, the storytelling group remained in a 'reflective' mode after telling their stories, going deeper into the feelings that were evoked and how others perceive them as people with disabilities. Based on Isaacs' (2008), I believe that the storytelling group conducted a *reflective dialogue* that led to a collective flow of ideas and feelings, rather than a *dialectic dialogue* that could have identified and resolved oppositions within their experiences.

A transition from reflective to dialectic dialogue may occur if storytellers are given more time to move beyond their interior experiences into the group dialogue where creative oppositions occur between the different stories.

I also believe that this transition would occur more readily if the group are given more deliberate encouragement and support to make this transition. In my case, I was alone as researcher, logistical organizer, and participant storyteller.

Kainkainen et al. report (2012) a very similar situation in their storytelling circle, and that, as a result, they created a new role of *creative secretary* in their second iteration of their method. This person was responsible for creative probes and encouraging participants to use projective language and metaphor as a way to move from reflection to a more structured, design-oriented dialogue.

The same effect may be achieved if other stakeholders (service providers, building managers, campus diversity consultants) were present in the storytelling group, since their perspective would presumably extend more deeply into the nature of the service design problems; however this would also pose challenges to the tellers' sense of safety and could reduce willingness to disclose their feelings and fears. Specific design affordances and constraints to avoid this risk would need to be developed if mixed storyteller-stakeholder groups are used.

5.8   Evaluation & Design Decisions

The story capture technique met some of the design objectives, and illuminated others.

It met the need to 'mobilize' lived experience and bring together unique experiences for use in online user-networks. Network collaborations could be designed to retain the whole-story format but allow for community tagging

John D. Willis

making information accessible to all, as a way of supporting the individual

storytellers' agency while also sharing knowledge.

I conclude that the stories captured in this project largely confirm the theoretical

value of using 'service-dominant logic' to conceptualize accessibility in lived

experience of service system breakdown. The story capture technique also

confirms the practical value of service design as an approach to specific

challenges that were illuminated in the stories. It is an effective way to generate

rich and structured information about concrete lived experience, including both

tacit and explicit knowledge of design challenges from the point of view of the

storytellers, aims and self-identity, sequences, feelings and concerns about the

future.

It also:

- Focusses the design process around 'holistic', or 'systemic', challenges of access design and experiences such as the prevalence of 'shadow work' or 'secret knowledge' that may be new concepts for some
- Yields sufficient detail and metaphorical content for use cases, journey-maps, quad charts, scenarios and other similar design tools

However, there are a number of learnings that pose challenges for the use of the

methodology in practical circumstances.

- The process revealed how difficult the transition to a collaborative design mode can be, especially when other stakeholders are not present. With the passage of time, storytellers 'move on' and self-accommodate, feeling less urgency to reach out to others for collaboration on a specific challenge that, at the time of telling their story, is in the past.

- The other key actors in the co-creation of access experiences are frequently not motivated to make change, and/or have existing patterns and incentives that mitigate *against* inclusive innovation. Some storytellers had reached out to other actors to request change in the affordances of a system (John, Adele, Graham) but other actors did not comply/reply.

- A significant amount of 'scaffolding' needs to be available to help participants shift from narrative reflection and sharing of experience to a problem framing, projection, and solution seeking. (cf. Kankainen, et al., 2012).[27] There was no existing collaborative team on which to model

---

[27] Evenson & Dubberly (2010) indicate that they used no less than 50 printouts of concept maps for that single article on the topic of innovation. Similarly the Preferences for Global Access project's phase of 'sketching' the first outlines of an eventual online 'discovery tool' for setting user preferences lasted four

new practices, and the storytelling circle thus resembled a focus group

more than a design team. This also fed a sense among some that they

would not want to take their stories directly to a web-enabled platform

or community. [28]

- Another very important learning is that stories tend to 'telescope'

  sequences and characters that are, in reality, highly dispersed (e.g.

  Samantha's issues finding housing).

- The stories cast a spotlight on the challenge of integrating user-

  innovation with the 'normal' processes of relevant organizations, but

  story capture does not provide a way to overcome the rigidities of

  existing organizational norms. Stable systems don't invite innovation,

  and existing feedback channels such as customer complaints lines are

  part of system optimization, not game-changing.

---

months with a kick-off face-to-face workshop followed by bi-weekly online

workshops hosted by two professional design facilitators.

[28] Vicki Cammack, founder of Tyze.org, explained in an interview (for a previous iteration of this project) that the dictum 'nothing about us without us' gets 'stretched' in the online context because it is easy to collaborate 'about' an individual with disabilities even if they are not present.

6. AccessMakers: A Platform for Inclusive Innovation

As outlined in the previous section, the participatory storytelling method was only partially successful in meeting the design objectives of this project. It is a powerful capture technique for user needs, and it bolsters individual esteem, however it is not sufficient to engage a specifically design- or innovation-oriented process.

Based on the participants in this study, I realized that there is insufficient 'modeling' of successful design collaborations around accessibility to inspire an online 'maker movement' community. In part this is a question of practice: "Being collaborative is much easier when you already have a team that is collaborating, and then you reach out to others, rather than trying to get everybody who is not collaborating to start collaborating," according to Gregg Vanderheiden, Director of the Trace R&D Center at the University of Wisconsin-Madison.[29]

A face-to-face practice, or model, may be necessary so that stakeholders can learn how an online platform may serve their needs.

As a second stage, I therefore decided to build a model of the circumstances in which the storytelling method could function with sufficient 'scaffolding' to

---

[29] Personal communication, February 15, 2015.

support a collaborative design process. Using my own experiences and those of the storytellers, I imagined an organizational setting in which stakeholders with disabilities – who might be employees, users, donors, clients, patients, customers, partners – could be engaged in a strategic collaboration to identify and resolve access barriers, and learn from the 'edge case' insights of people who experience them. Motivations to undertake this process could be mundane (meeting regulatory requirements for accessibility compliance) or aspirational (driving innovation in services or products, solidifying mission, etc.).

I created early prototypes of what I call 'AccessMakers' to illustrate how a collaborative design process could be developed on the basis of the story capture technique.

- AccessMakers inclusive innovation workshops to bring together the 'locus of knowledge' (people who experience access barriers) with (potential) 'loci of innovation' (organizations, companies, public agencies) (full modules)
- AccessMakers online innovation community (indicative wireframes)

Lack of time in this project meant that I could not conduct a full participatory method for this second prototype, however they were circulated to what I take to be 'typical' users and their feedback is reported below.

6.1 AccessMakers Inclusive Innovation Process[30]

There are six modules in total – two introductory statements, three workshop modules, and one outline of digital tools to support the organizations that engage with AccessMakers.

1. **Why be Inclusive?** How inclusive design can drive innovation and creativity in your organization: Introduces core ideas of inclusive design such as the value of 'edge cases' as a spur to innovation, and the organizational advantages of 'inclusive leadership'. (Treviranus, 2014a/b; Talent Innovation Taskforce, 2014; Smedley, 2014; IDRC, 2013; Page, 2007)

2. Access to what, exactly? Highlights the sorts of insights that people with disabilities can bring to organizations in both the public and private sectors. This module includes a brief overview of findings from the stories in this project and of the AccessMakers method.

3. Discovery Through Storytelling – The first module of the AccessMakers method shows the user how to setup and run a 'discovery process' for innovation, using the story capture technique ("bring 'lived experience' of people with disabilities into your innovation and design process"). This module emphasises listening and sharing of stories in a respectful and

---

[30] The modules as presented to users in prototype format are in Appendix D.

safe environment. Users are informed that financial compensation to stakeholders is part of the AccessMakers method.

4. **Knowledge & Trust: Making Progress Together** In the second workshop module, users are introduced to two techniques for sharing new learning across boundaries of skill, internal silos, and embedded cultures. Problem framing is the focus, linking access barriers from stories (first workshop) to organizational priorities and challenges to create a new design space for innovation.

5. **Innovation & Inclusion –** In the final workshop module, the focus is on identifying a wide range of solutions that could remove access barriers and, at the same time, drive valuable innovation for the organization or its members. The workshop module invites users to consider the most desirable modes of innovation for their situation, and introduces human-centred design methods without suggesting that existing practices be jettisoned.

6. **Digital Supports & Online Community** – Shows users how AccessMakers can work to their advantage as a powerful online community. This component is reviewed in the next subsection.

6.2   Visual Identity: Disability and Innovation

In order to express the core values of AccessMakers, I conceived a visual identity that uses traditional symbols for accessibility but modifies them to put a strong focus on the role of people with disabilities as creators and innovators. With the help of Tomasz Pokinko, an inclusive and visual designer, the following three symbols were developed (Figure 7).

Figure 7: The Visual Identity of AccessMakers[31] (credit: John Willis/Tomasz Pokinko)

The set intentionally reference the well-known international symbols for access but alters them to challenge our assumptions about the role of the person with a disability (either as a passive consumer or an outlier not worth designing for). The set consists of:

- White cane/paintbrush - Contradicting our expectations, the familiar blind figure lets loose a colourful expression of visual design from their 'cane-brush'.

---

[31] These symbols, and variations, are licensed under Creative Commons with the name **Differability Symbol Set by John Willis & Tom Pokinko.** See page ii for copyright notice.

- Musical signing - Artistic creativity finds boundaries and then transcends them, such as when a musician without hearing nonetheless uses physical vibration or visual notation as their mediums of musical expression.

- Power onboard! - This symbol of a computer power-button superimposed on the 'classic' wheelchair access symbol elegantly puts to rest the old stereotype of disability as a passive state of limited or non-existent creativity.

6.3   Input from Users

The prototype outlined here and fully shown in Appendix [x] was distributed to potential users in March, 2015. They were asked to review all components from their professional perspective and provide feedback in a short (6-question) Google Form survey.

These users were:

- Cathy Cappon, Accessibility Manager at OCAD University in Toronto

- Ather Shabbar, Senior Researcher & Policy Advisor at Ontario Public Service (Ministry of Transportation)

- Bernita B. Lee, Diversity Consultant at the City of Toronto

- David Kraft, a specialist in strategic planning working with not-for-profits, labour unions, social enterprises, and community groups.

General: Users expressed generally positive feedback on the rationale for inclusion and the flexible design of the workshops and online community. *"The rationale for inclusion as driver for innovation is compelling... Tackling this issue of inclusion/'edge" employees and clients would be potentially a real breakthrough for us. It would be a big step toward becoming the organization we aspire to be in relation to our clients/customers,"* said one. *"[It is] practical and adaptable to most environments. I believe it would be a useful tool in fostering engagement, sharing knowledge and of course addressing the access challenges one may face..."* said another. A third, working in a large institutional setting, said *"the approach to meaningful, respectful engagement is excellent and [is] one that is needed both in community collaboration and in research practice."*

Metrics & Outcomes: Two respondents spoke of the need to clarify outcomes. One said that many potential users in government would, in their view, need to see 'case studies of success' before they would adopt AccessMakers. The same individual said that this would be a good way to encourage 'lead innovators' (von Hippel, 2002) to emerge in the community. Another, in an SME, said *"...without undermining the inherent open-ended creativity of the methodology, (I believe) companies like mine*

need fairly clear metrics for inputs>outputs>outcomes (or at least the range of outcomes they can expect)."

Disability focus: One user felt that AccessMakers erred a bit too much on the side of 'innovation' - "*...disability is central to the project, [yet] disability continues to sit on the periphery of the project and [is] defined as inclusive design and disability - as if the two of these are exclusive.*" They also reminded me that *"many people with disabilities are the ones affecting change."*

Multi-purpose: Prompted**,** all users said they thought that AccessMakers could be used for strategic planning, research (like focus groups), design/development, or leadership training purposes. A respondent in government also said that the process could be adapted to many contexts where there are risks of marginalization and a need for inclusive practices, such as in public health, schools, and community policing.

Specificity: By the same token, though, another user said that the prototypes suffer from language that is too general. "Any instructive language in your document needs to be consistent and geared to the audience (executive/senior staff, middle managers, front-line? in our case, elected officials?)" This is similar to the experience that the Inclusive Design Research Centre (IDRC) has had in working with the Ontario Public

Service (OPS): "The tool or process needs to be inclusively designed,"

according to inclusive designer Jutta Treviranus, in order to benefit as

many stakeholders as feasible.[32]

6.4   Evaluation and Next steps

The AccessMakers workshops and online supports appear to successfully model

the kind of collaboration that I want eventually to build up in an online

community. The story capture technique can play a key role, although the

workshops will need to be refined and their appeal to different possible users

clarified. More specific outcomes need to be defined.

Many questions of a more fundamental nature remain. Next steps in the design

process should consider:

> **Who Pays?** I have not touched on how revenue and rewards could be
>
> generated or distributed. For multi-stakeholder platforms in business,
>
> this is a key consideration and in the 'maker movement' as well,
>
> sustainability is key to maintain confidence of community members.
>
> (Hagiu, 2013) I recommend investigating badging and recognition
>
> systems as part of this, especially the potential to give marginalized or
>
> socially-isolated individuals recognition for their knowledge and insight
>
> about the 'breakdown' of affordances that we all share.

---

[32] Personal communication, April 29, 2015.

Validating and Extending the Story Capture Technique: It would be ideal to know more about the practical value of the story capture technique in different domains, e.g. on campus, in workplaces, in retail settings, in a police force or transit system or hospital or public health unit.

Validating the Workshop Process: Based on the feedback of users in this report, test a functional prototype of the workshops, with greater emphasis on defining potential outcomes for users. Ensure full participation of people who experience access barriers, throughout the prototyping and evaluation.

Affordances for customer experience professionals: Could AccessMakers be a professional service for customer experience (CX) and user experience (UX) design? Could this support the platform as a revenue stream and generate revenue to pay storytellers for their work?

Live Online Prototypes (Pilot Phase): The online platform described here needs to be prototyped and tested. This could be done with a small community of storytellers and two or three cooperating enterprises, public agencies, or non-profits. This is the best way to find out what the design decisions are for AccessMakers as an online community. This sub-project should include developing a **technology roadmap,** in which I

recommend special attention to the affordances of existing social media platforms as channels for storytelling into the AccessMakers community (instead of creating new tools and interfaces).

For example, Storify, Twitter, Google+ and Pinterest each provide tools for a user to tell a story at the moment of the experience and can be linked to an AccessMakers website or web app to add content, engage in community tagging, and share or re-post in other forums such as a user's blog or website. In this way, users could create portfolios and link them to organizations via AccessMakers, without necessarily having to adopt and learn a new social networking interface.

6.5   Epilogue: AccessMakers Online

Although there were concerns raised by some participants in the storytelling group about taking their stories 'online', appropriate design could turn AccessMakers into a powerful online community. In this project I outlined some of the possibilities for users to take
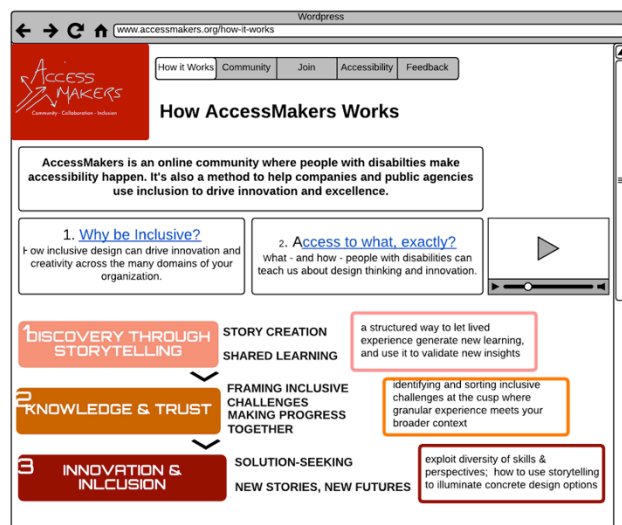
Figure 8: 'How It Works' Wireframe, AccessMakers Online

77

advantage of digital supports, not a full prototype of a functioning community.

Through an online version of AccessMakers (see Module 6 in Appendix D), stories could be collected from individual users either through workshops or via crowdsourcing. Individuals who experience access barriers would log their stories, using a structured interface that reflects the story capture technique reviewed here. Storytellers could create a 'journal' to collect, sort, and manage their stories.

Organizations using the workshop process could create a portfolio of stories relevant to their priorities and stakeholders. Individuals could choose to contribute to any organizational portfolio (through crowdsourcing), even if they have not attended a workshop. In this way, companies and agencies would have a robust feedback loop with users, and customers or users would have a robust feedback channel devoted to finding access solutions.

Table 2 suggests how 'heavy' and 'lightweight' tasks can be distributed and accomplished on AccessMakers. (Haythornthwaite, 2009)

actor	'lurk' (online)	light	medium	heavy
Individuals seeking solutions	Learn/build identity by reading online stories	Community tagging (to add knowledge to the network)	Participate in sponsored workshops; create Story Journal	Collaborate with designers/organizations on specific projects
Designers, developers, planners, entrepreneurs	Learn/build identity by reading online stories	Community tagging	Promote AccessMakers in professional networks/clients	Collaborate on projects
Companies, agencies, orgs	Learn/build identity by reading online stories	Collect online stories relevant to mission/ priorities; community tagging	Sponsor workshops with stakeholders (employees, customers, etc.)	Sponsor workshops; collaborate on projects; build portfolio of projects

Table 2: Roles in AccessMakers Online Community

As stories accumulate, community knowledge would aggregate around commonly identified problems, reducing up-front innovation costs for organizations to remove access barriers. Participation in the community would build knowledge in organizations and help them comply with legal standards for accessibility.

Even if a company had not sponsored an AccessMakers workshop, they could still be profiled by the accumulation of stories related to their access barriers.

Storytellers would always 'own' their own stories, regardless of whether they offered it through a sponsored workshop. They could choose whether to open their stories for community tagging – if they opt to, others could then add metadata such as design options or specifications, or 'fill in the blanks' if, e.g. a story lacks specific enough details to start a collaborative team.

John D. Willis

Similarly, companies and organizations that use the AccessMakers method could log their learnings and successes for others to benefit, with community tagging being a method for sorting and searching.

Eventually a fully-functioning AccessMakers could become a multi-stakeholder 'maker platform' with design tools and resources, lead innovators, crowdsourcing of user research, and metrics to support companies, local governments, public agencies and non-profits to measure outcomes relevant to their stakeholders. Using community tagging, stories could be expanded sorted, searched, used and re-used, but remain intact and available to communicate in a holistic way for various design projects. In this way, AccessMakers can be both an innovation platform and a way of promoting emancipation and participation for its users with disabilities.

7. Concluding My Journey

> *"Disability is both a cause and a consequence of poverty: poor people are more likely to become disabled, and people with disabilities are among the poorest and most vulnerable groups of the global population."* (ITU, 2013, pg. viii)

> *"Design thinking needs to be turned toward the formulation of a new participatory social contract."* (Brown, 2005, pg. 178)

My first steps on this journey used my experience as a guide to some of the barriers that interfere with activity and pursuit of life goals for millions of people. As my investigation progressed, the possibilities of a web-enabled peer-production network strongly inspired me. The sheer pervasiveness of the world wide web and the potential of a truly global and public infrastructure for digital communication seem to mirror the ubiquity of access barriers. The complexity and granularity of the 'design space of inclusion' *can* be encompassed by the distributed, participatory world wide web. This amazing platform and toolset requires new social

practices and structures
– individualized
networks for
innovation and
creativity, people acting
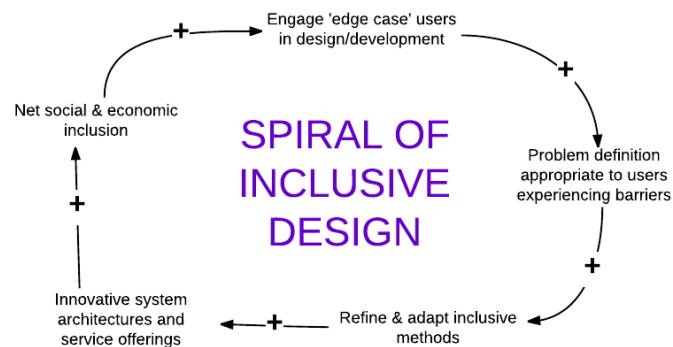
Figure 9: The Virtuous Circle of Inclusive Design

as prosumers not only for their own needs but for their communities as well.

There are many questions still to be resolved, and deep-rooted power structures remain in spite of the real disruptions of the new digital era. But the future can be different if we enable inclusive feedback loops at all levels – starting with participation for people at the social and economic margins, leading to better problem identification and adaptation of methods to be more inclusive, in turn creating better products and services that, drive greater participation for all (a virtuous circle that is illustrated in Figure 9).

I created AccessMakers, based on the story capture technique outlined in this report, as a way of mobilizing, aggregating and using direct user experience to design access solutions. It is both a process that enables individuals and networks of collaborators to scale inclusive design spirals in small or large organizations, public or private sector, online or offline (and, preferably, both).

I believe that the designs reported here can, if fully developed, meet the key objectives set out in Section 4, namely:

- Mobilize and aggregate users' lived experience of access barrier experiences

- Support collaboration in networks of organizational as well as individual actors

- Support collaborations offline or online

- Encourage and enable innovations that benefit diverse needs and/or stakeholders.

My greatest learning has been that while we need to be inclusive for people with disabilities, positioning them as user-collaborators also requires that we be inclusive of *each and every actor that we need as a collaborator*. We need techniques and processes that liberate all collaborators from pre-ordained tools, methods, expectations, and even incentives. Liberated networks are the foundation of true inclusion – new social practices in a participatory web.

7.1   Contributions to Inclusive Design

I tried to make this whole project an inclusive design spiral, based on the definition of inclusive design that I gave on page 22. First, I think it has a profound appreciation of diversity in the needs, abilities, and perspectives of people with disabilities. I also tried to incorporate diversity among other AccessMakers stakeholders, giving them a process that is adaptable and flexible to their requirements.

Second, as much as I could manage in six months, I tried to use co-creation as a method for developing the prototypes. I learned how difficult that can be, requiring a good deal of support to participants and this gives me a greater appreciation of the challenges faced by all inclusive designers.

Together the story capture technique and AccessMakers are a platform for innovation. They are flexible, adaptable processes for identifying and creating 'one size fits one' design options. It is a deliberate feature of the AccessMakers workshop design that it should support the creation of benefits for all actors, in addition to people with disabilities. This feature of inclusive design generally is critical to motivate networks and institutions to embed inclusion deeply into their own learning and evolution.

Narrative Inquiry: I also believe that my choice of first-person narrative (storytelling) as both a stand-alone design research method and as a process for collaboration is valuable to the field. I strongly believe that it is a very appropriate technique for bringing together threads of meaning in highly dynamic and sometimes ephemeral experiences, despite its limitations in the format that I prototyped. I hope this report is of use to other practitioners interested in using it for related purposes.

Filling Out the Design Definition of Disability: This was an effort to ground the design definition of disability by showing that what we are designing *for* can be understood more deeply through a service design lens, as opposed to a product design lens. I also tried to clarify that access barriers are 'edge cases' distributed in every domain and system and product. They are everywhere – as pathways to innovation and positive development.

Collaboration is a User Requirement: That is the theory. The practical lesson I hope to reinforce is this: Access barriers are a co-creation between individuals and other actors, structures, and practices – which means that *collaboration and participation are user requirements* when it comes to finding solutions. It is not a 'good to have' but a 'need to have' for reasons of design as well as reasons of history. Let's not make old mistakes again by reducing people with disabilities to abstract personas and lists of 'user needs' that are to be managed by professional designers, marketers and 'experts'.

Accessibility can be part of the terrain on which to 'train' ourselves in a new set of social practices that are inherently empowering and engaging for people of diverse abilities and experiences. That is the biggest 'curb cut' of all – a mass network of prosumers of all abilities, engaged in constant social innovation and accustomed to participatory problem-solving.[33]

7.2   Where Next?

I hope that I have demonstrated the *desirability* of user networks for collaborative access design. Their viability and feasibility are sketched here, but

---

[33] There is an echo here of the concept of *unself-conscious design* as developed by Alexander in the field of architecture, in his 1964 book *Notes on The Synthesis of Form.* He is contrasting the way that people will often modify their spaces and structures as their needs or desires evolve, without establishing hierarchical roles for expert designers (such as architects) and without highly formalized knowledge-management tools (such as detailed blueprints and specifications for construction that are used to control design processes).

we need to know more in order to bring about our desires in this vast and dynamic field.

I have based these observations and my analysis quite firmly in my own experience, as I consider this an important touchstone of inclusive design. Other researchers and designers will naturally have different – hopefully very different! – life experiences that will give them unique insights into how we can move forward. I look forward to practical as well as theoretical experimentation and re-purposing of the user network that I have outlined here.

In particular, I recommend a focus on:

Case studies – Assembling **e**xamples of user networks and collaboration around inclusive design is one way to refine our understanding of the social norms, process, and techniques that make collaboration more or less successful.

Storytelling in leadership – One of the dimensions of storytelling that I chose to leave out of this analysis is its role in organizational leadership and development. Stories are a powerful way of helping organizations communicate their mission or priorities to employees, shareholders, regulators, and their customers, and are also very important in the formation of social movement leadership around public concerns such as the treatment of people with disabilities. Research is needed to understand if the story capture technique can be modified for use in mobilizing organizational stakeholders for service system

innovation. In other words, a story of user experience is valuable for a design process, but stories that are about successful user-innovation may be more useful for convincing other stakeholders to participate.

Pattern language – In service systems management there is an interest in using Alexander's notion of *pattern languages* to identify recurring problem in service systems and to give the field of service systems design a holistic approach to its subject.[34] Alexander did not mean a standardized methodology or universal set of solutions, but rather an expression of the wisdom built up in a discipline that has confronted challenges within a domain repeatedly over time, and he used the word 'aliveness' to connote the organic character of pattern languages. (Alexander, 1977) If a pattern language of service systems is eventually established, it should be possible to extend and modify it into the domain of access design. This step could advance our ability to unify and communicate access design learnings and concepts through user networks that connect seamlessly to the patterns that commercial service designers work with every day.

Who is engaged – in my research, I had eight storytellers, and all of them were well-educated individuals of working-age. How do AccessMakers and other inclusive innovation platforms need to be modified for older individuals, people

---

[34] 'Proposal for Collaboration on a Pattern Language for Service Systems', at http://coevolving.com/blogs/index.php/archive/a-proposal-for-collaboration-on-a-pattern-language-for-service-systems/, accessed March 22, 2014.

with complex needs, or who live in supported communities such as long-term care homes or group home settings? What are the social constraints and affordances in play and how should we design for them?

Advocacy/design – More research is needed to understand the conditions under which organizations and companies would engage with their customers or the public through AccessMakers. If there is resistance, for whatever reasons, should the platform be optimized as a space for advocacy to build social pressure on 'un-cooperative' stakeholders? Would that conflict with the norms of an inclusive design platform?

Unique role in a worldwide community– A related question is how AccessMakers differs from other emerging platforms that seek to create markets or developer tools for collaborative design, such as the **OmniAgora** mentioned in Section 3.3? It would be very interesting to look at the overlap of the various online communities and platforms that are now emerging, to understand how users are being served and whether there are unmet needs that can be fulfilled by AccessMakers.

References

AdCiv.org (2010). Open collaborative design (web document).

Alexander, C., (1977). *A Pattern Language: Towns, Buildings, Construction*.

---- (1964). *Notes on the Synthesis of Form* (Vol. 5). Harvard University Press.

Aragon, C. R., & Williams, A. (2011). Collaborative creativity: a complex systems model with distributed affect. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (pp. 1875-1884). ACM.

Bold, C. (2011). *Using Narrative in Research.* (Kindle for iPad version). Retrieved from Amazon.ca.

Budhathoki, N. R., & Haythornthwaite, C. (2013). Motivation for open collaboration crowd and community models and the case of OpenStreetMap, *American Behavioral Scientist*, *57*(5), 548-575.

Brown, T. (2014). *Change by design*. HarperCollins e-books.

Brudney, J. L., & England, R. E. (1983). Toward a Definition of the Coproduction Concept, *Public Administration Review, 43(1),* pp. 59-65.

Buxton, B. (2007). *Sketching User Experiences: Getting the Design Right and the Right Design.* Morgan Kaufmann.

Chadwick, D., Wesson, C., Fullwood, C. (2013). Internet Access by People with Intellectual Disabilities, in *Future Internet 2013.*

Chambers, P. (2003). Narrative and reflective practice: recording and understanding experience. *Educational Action Research*, *11*(3), 403-414.

Chesbrough, H., (2011). Bringing open innovation to services. *MIT Sloan Management Review, 52(2)*, 85-90.

Church, K., Frazee, C., & Panitch, M. (2007). Out from under: Disability, history, and things to remember. Royal Ontario Museum exhibit and online catalogue, http://www.ryerson.ca/ofu/about/index.html

Coleman, B., (2014). An inflection point. In Chourasia, A., et al, (Eds), *State of the science on the Cloud, accessibility, and the future*. SpringerLink.

Costa, L., Voronka, J., Landry, D., Reid, J., Mcfarlane, B., Reville, D., & Church, K. (2012). Recovering our stories: A Small Act of Resistance. *Studies in Social Justice*, *6*(1), 85-101.

Csikszentmihalyi, M. (2008). *Flow: The Psychology of Optimal Experience.* HarperCollins eBook.

Denning, S. (2011a). *The leader's guide to storytelling: Mastering the art and discipline of business narrative.* Jossey-Bass.

—–, (2011b). Why leadership storytelling is important. *Forbes.com.*

Dubberly, H. (2008). COVER STORY Toward a model of innovation. *interactions*, *15*(1), 28-36.

Enkel, E., Gassmann, O., & Chesbrough, H. (2009). Open R&D and open innovation: exploring the phenomenon, *R&D Management, 39(4).*

Evenson, S., & Dubberly, H. (2010). Designing for service: Creating an experience advantage. *Introduction to service engineering*, 403-413.

Forlizzi, J., & Battarbee, K. (2004, August). Understanding experience in interactive systems. In Proceedings of the 5th conference on Designing interactive systems: processes, practices, methods, and techniques, 261-268. ACM.

Forte, A., Larco, V., and Bruckman, A. (2009). Decentralization in Wikipedia governance, *Journal of Management of Information Systems, 26:1,* 49-72.

Fox, S., & Boyles, J.L. (2012). Disability in the Digital Age (web document). Pew Internet.

Galarneau, D., and Radulescu, M. (2009). Employment Among the Disabled (web document). Statistics Canada.

Gassmann, O., & Enkel, E. (2004). Towards a theory of open innovation: Three core process archetypes. In *R&D management conference* (Vol. 6).

Gassmann, O., Enkel. E., and Chesbrough, H. (2010). The future of open innovation. *R&D Management, 40(3),* 215-221.

Gharajedaghi, J. (2011). *Systems thinking: Managing chaos and complexity: A platform for designing business architecture, third edition.* Elsevier.

Gill, K. (2012). Usability of public web sites. Ch. 2 in Buie & Murray (Eds.), *Usability in Government Systems: User Experience Design for Citizens and Public Servants,* (Kindle for iPad version). Retrieved from Amazon.ca.

Glushko, R.J. (2010). Seven contexts for service system design. Chapter in Maglio, P. P. et al, (eds.) *Handbook of Service Science: Service Science Research and Innovations in the Service Economy.* Springer Science+Business Media.

Gold, J., & Hjartarson, J. (2012). Integrating Human Services in an Age of Fiscal Restraint. Mowat Centre for Policy Innovation.

Gorry, G. A., & Westbrook, R. A. (2011). Can you hear me now? Learning from customer stories, *Business horizons*, *54*(6), 575-584.

Hagiu, A., (2014). Strategic Decisions in Multi-sided Platforms (MSPs), *MIT Sloan Management Review, Winter 2014*, 71-79.

Haight, M., 2014. Revisiting the digital divide in Canada: The impact of demographic factors on access to the internet, level of online activity, and social networking site usage, *Information, Communication & Society*, *17(4)*.

Haythornthwaite, C. (2009). Crowds and Communities: Light and Heavyweight Models of Peer Production. *Proceedings of the 42nd Hawaii International Conference on System Sciences.*

Helkkula, A., (2010). Narratives and metaphors in service development, *Qualitative Market Research: An International Journal.*

Helkkula, A., Kelleher, C., and Pihlström, M., (2012). Characterizing Value as an Experience: Implications for Service Researchers and Managers, *Journal of Service Research 15:59*.

Holmes, B. (2011). Citizens' engagement in policymaking and the design of public services. Canberra: Parliamentary Library, Federal Houses of Parliament, Australia.

Hughes, Z., and Brennan, C. (2010). 'The Wheel Always Turns in Circles': Accessible Report of the 'A Story to Tell' Lifestories Project. National Institute for Intellectual Disability, Trinity College Dublin.

Inclusive Design Research Centre (IDRC), (2013). *The three dimensions of inclusive design.* Web document.

John D. Willis

International Telecommunication Union (ITU), (2013). *The ICT Opportunity for a Disability-Inclusive Development Framework: Synthesis report of the ICT Consultation in support of the High-Level Meeting on Disability and Development of the 68th Session of the United Nations General Assembly.*

Iriberri, A., & Leroy, G. (2009). A life-cycle perspective on online community success. *ACM Computing Surveys (CSUR)*, *41*(2), 11.

Isaacs, W. (2008). *Dialogue: The art of thinking together*. Crown Business.

Jackl, A., Treviranus, J., Roberts, A. (2004). IMS AccessForAll Meta-data Overview. Web document at http://www.imsglobal.org/accessibility/accmdv1p0/imsaccmd_oviewv1p0.html

Jones, P. (2014). Systemic design principles for complex social systems. In G. Metcalf (ed.), *Social Systems and Design.* Springer Verlag.

Kankainen, A., Vaajakallio, K., Kantola, V., & Mattelmäki, T. (2012). Storytelling Group–a co-design method for service design. *Behaviour & Information Technology*, *31(3)*, 221-230.

Kavanaugh, A., Carroll, J. M., Rosson, M. B., Zin, T. T., & Reese, D. D. (2005). Community networks: Where offline communities meet online. *Journal of Computer-Mediated Communication*, *10*(4), 00-00.

Keeley, L., Walters, H., Pikkel, R., & Quinn, B. (2013). *Ten types of innovation: The discipline of building breakthroughs*. John Wiley & Sons.

Keese, M. (2006). *Live longer, work longer*. Organization for Economic Cooperation and Development (OECD).

Kelly, K. (2005). We are the Web, *Wired Magazine, Issue 13.08, August 2005.*

Kimbell, L., and Julien, J., (2012). The social design methods menu (beta). Web document, Fieldstudio Ltd.

Kleemann, F. G., Voss, G., and Rieder, K. (2008). Un(der) paid Innovators: The Commercial Utilization of Consumer Work through Crowdsourcing. *Science, Technology & Innovation Studies 4.1:5.*

Lakhani, K, & von Hippel, E. (2003). How open source software works: "free" user-to-user assistance. *Research policy, 32(6),* 923-943.

Lanier, J. (2014). *Who owns the future?* Simon and Schuster.

Lehoux, N. (2013). Interaction that values co-creation in the design of services. *Bell Labs Technical Journal 17(4),* 145-156.

Maglio, P. P., and Spohrer, J. (2008). The emergence of a service science: Toward systematic service innovation to accelerate co-creation of value. *Production and Operations Management, 17(3),* pp. 238-246.

McCandless, K., and Lipmanowicz, H. (2014). The Liberating Structures Menu. http://www.liberatingstructures.com/ls/.

McGrenere, J., and Ho, W. (2000). Affordances: Clarifying and evolving a concept. *Graphics Interface (Volume 2000),* 179-186.

Melchior, L., Spaitehotz, L., Syme, R., Kay, K., (2011). *Digital Dialogue: An Analysis of Social Media Access for People with Developmental Disabilities.* University of Victoria.

Morville, P. (2004). User experience design. Semantic Studios, www.semanticstudios.com/user_experience_design/

Nornan, D. (2013). *The Design of Everyday Things (revised and expanded).* Basic Books (Kindle edition).

Oehlberg, L., Roschuni, C., and Agogino, A. (2011). A descriptive study of designers' tools for capturing, reflecting on, and sharing user needs and conceptual designs, in *ASME 2011 International Design Engineering Technical Conferences and Computers and Information in Engineering Conference* (pp. 199-208). American Society of Mechanical Engineers.

Page, S. E. (2007). *The Difference: How the Power of Diversity Creates Better Groups, Firms, Schools, and Societies.* Princeton University Press.

Pinhanez, C. (2009). Services as customer-intensive systems, *Massachusetts Institute of Technology Design Issues: Volume 25, Number 2 Spring 2009,* 3-13.

Portigal, S. (2008). Persona non grata. Web document at http://www.portigal.com/wp-content/uploads/2008/01/Portigal-Consulting-White-Paper-Persona-Non-Grata.pdf. First published in *INTERACTIONS-NEW YORK-, 15*(1), 72.

Rogers, Y., Sharp, H., & Preece, J. (2011). *Interaction design: beyond human-computer interaction*. John Wiley & Sons

Tapscott, D., & Williams, A. D. (2007). Innovation in the age of mass collaboration. *Bloomburg Business Week* (online), 1 February 2007.

Treviranus, J. (2013). Public policy and the global public inclusive infrastructure project. *interactions*, *20*(5), 62-66.

—– (2014a). Leveraging the Web as a Platform for Economic Inclusion. *Behavioral sciences & the law*, 32(1), 94-103.

—– (2014b). The value of the statistically insignificant, *EduCauseReview*, January 2014.

Treviranus, J., & Hockema, S. (2009). The value of the unpopular: Counteracting the popularity echo-chamber on the Web. In *Science and Technology for Humanity (TIC-STH), 2009 IEEE Toronto International Conference* (pp. 603-608). IEEE.

Treviranus, J., Clark, C., Mitchell, J., & Vanderheiden, G. C. (2014). Prosperity4All– Designing a Multi-Stakeholder Network for Economic Inclusion. In *Universal Access in Human-Computer Interaction. Design for All and Accessibility Practice* (pp. 453-461). Springer International Publishing.

Vanderheiden, G. (2006). Design for people with functional limitations. *Handbook of human factors and ergonomics, Fourth Edition.*

Vargo, S. L. and Lusch, R. F. (2004). Evolving to a new dominant logic for marketing, *Journal of Marketing* 68 (January): 1–17.

Vargo, S., Paul, L., Maglio, P., and Archpru Akaka, M. (2008). On value and value co-creation: A service systems and service logic perspective, *European Management Journal* 26, pp 145-152

von Hippel, E., (2007). Horizontal innovation networks—by and for users. *Industrial & Corporate Change (2007) 16 (2): 293-315*

von Hippel, E., & Katz, R. (2002). Shifting innovation to users via toolkits. *MIT Sloan School of Management, Working Paper 4232-02*.

Wilkinson, R. and Pickett, K. (2009). *The Spirit Level: Why Greater Equality Makes Societies Stronger*, Bloomsbury USA.

Williams-Ng, S. (2014). 'Storytelling for designers', video at
http://www.lynda.com/Design-Design-Skills-tutorials/Connect-your-audience/165645/193578-4.html

Wise, S., Paton, R.A., and Gegenhuber, T. (2012). Value co-creation through collective intelligence in the public sector: A review of US and European Initiatives. *VINE, 42(2),* 251-276.

APPENDICES

A – Stories

B – Online Dialogue and Second Workshop Protocols

C – Story Structure & Representations in Service Design Tools

D – AccessMakers Modules

Appendix A: The Stories

Adele's Story

Critical Incident? *When I was told 'your visual impairment won't be an issue in whether we hire you,' and then when I was hired and they said 'it won't work' and I just had to make it work.*

My story is about an aspect of employment we don't often think about, which is that even if you get a job and even if you get somebody who's good enough to give you a shot, your software, the software they use, might not be compatible with ZoomText [screen magnifier] so you can't do your job.

So it's another barrier, not only do you need to convince them that you're good enough, that you're fast enough, then you get there and it's 'no, our system is not compatible' – so what can you do?

I was in my early 20s, I was going to school to get my first degree – and it was after the first year of school, I was about 21 or 22 years old – I didn't yet know about the loans and bursaries program that allows all loans to become bursaries if you have a disability.

i was tired of feeling like a burden on my family, since most people start working at 17 or 18 (years of age) and i wanted to have a job to help pay for myself.

I ended up applying to a survey interviewing situation, a phone room with cubicles. But jobs re limited when you can't see well, it's not like I can work at a restaurant… spilling hot coffee on customers… so I felt like 'yeah I can talk on the phone'.

First, I went to [local low-vision rehab institution] and basically I was told it's very difficult to get a job. This counsellor had a reputation for always placing people at McDonald's — but with my depth perception he said even McDonald's wouldn't be a good idea.

When I mentioned the idea of being on the phone and doing surveys, he said 'you don't really have the personality for it, and I wouldn't support you in that'.

So, this is the first time I ever see somebody related to employment and that's what I'm told.

Anyway, I ended up getting the interview [for surveying] on my own, and I was really trying to prove myself. I mentioned in the . Interview that I needed accommodation and it's pretty obvious in my resume. And when I went to the interview I showed up with my cane folded, I don't need it when I'm indoors, I am legally blind but I have vision.

The person doing the hiring said 'don't worry we won't count your visual impairment when I make a decision'. She had no clue what ZoomText was but they said we'll look into it, they seemed very accommodating. When they called back and said 'you got the job', they said their technician would look into it.

But they couldn't get it to work, and I couldn't get it working…

John D. Willis

But I have some vision, and so every time I went into the office I would advance the computer screen as much as I humanly could, and I would prop up the keyboard onto the computer screen. They did make accommodations – (for example) most people would go to a big board where they would find out where to sit and get information for their shift… but I couldn't read it so I had to go to a person to ask, and they would look it up for me, they accommodated that.

But basically ZoomText wouldn't work and I couldn't make it work, it was not compatible with their software. It was not like you could go to the internet, because their software was the only thing I had access to on the computer.

I managed to hold onto the job for about eight months, it was not the easiest thing. I was not very productive. They had four tiers, so people at tier 1 or 2 got to choose their work assignments first, and if you were lower then you got the 'leftovers' – it was hard to know if that was because I can't see well, or if I just am not that type of personality.

For example, I would get remarks about not reading the script word-for-word, I don't know how often they just didn't tell me I was making a mistake… I'm supposed to read word-for-word on the screen, but I didn't have a screenreader or a magnifier!

I ended up quitting… they had a '5 strikes you're out' type thing, so if you cancel your shift last-minute, those sorts of things. And one time – they were really nice about it — I misread the time on the screen and left an hour

early! I noticed it later and called them later in a panic saying 'I'm sorry!'

I think that I worked from May to November, and then I had final exams coming up so it was a combination of school being too much but also I was on that borderline and if I made one more mistake….

This was my first experience of this kind, 'out there on my own' and then I get there and not only don't they have ZoomText but there are these 15" monitors. I'm thinking 'what do I do..?' I didn't want to just give up, but at the same time I didn't know how to make it work so I was trying a few things, trying without [ZoomText] –

What I remember most is not wanting to fail, wanting to persevere, trying to be creative like you know propping the keyboard up onto the monitor so I could get as close as possible would actually work…

It was a very new situation, it was important to me even though it wasn't a career path, I wanted to pay my own tuition and support myself because my mother doesn't make that much money and I believe in being independent.

April's Story

Critical Incident? I was upset that I'd been invited to this event and told it was accessible, then staring at the door and the step and realizing I couldn't tell how to get into the building.
I was going to *The Old Spaghetti Factory* for a film workshop – I'm an actor – with people exploring scripts,

by getting up and reading scripts, and I'm an actor so this interested me, and it's also a way of connecting with other actors and writers in the industry and seeing if I could carry the networking forward, get some feedback, whatever.

When I tried to go into the restaurant, I went to the main entrance and there was this huge step, and these big doors and no apparent other access. It wasn't until somebody came out – and I was taking a photo of the door and the step to show there was no access – so I questioned them about how I was supposed to get in. I mean I could just get somebody to tilt me back and push me up the step, which is what I usually do, but I was invited to this event and they assured me it was accessible, and supposedly it was – through another entrance that wasn't even really the same restaurant. And apparently everyone who knows that thinks that everyone knows it – there is no signage to indicate it.

I was really bent out of shape about it, and when I got in, I connected with two other friends who – one uses a motorized scooter and the other uses a chair – they were not bent out of shape about it because they knew the alternate entrance. I was really miffed by the organizers as well as the managers and all the rest of it. I mean: simply put up a sign. I'm not asking you to build a ramp, just make people aware of how to get in.

There's only so much time and there's so much to accomplish at those events. I wrote up my frustrations and sent it out to some friends to get feedback and I was going to send it to the organizers and the managers, and find some place to air my grievance –

even the restaurant website doesn't say 'there is alternate access at so-and-so location' and if someone with a visual impairment… I mean there's a variety of people who need better information.

If I wasn't going there for an event that I was committed to, because I was reading a script, I would have left. I would not have gone in. And that's bad for business. I did let a few people know, I did try to raise it, but even on the website there was no… there was no way to complain.

You put a wheelchair symbol on it, and think that means it's accessible, people figure that it's not necessary to explain where the entrance is. It's bad for business, you don't know how many people decided not to go to that restaurant because it's not accessible. It's not like the entrance is next door, it's 2 doors down.

It's not an uncommon experience. I voiced my concerns with a few people there, that i knew would hear what I had to say, and I was surprised that my fellow wheelers were not very outraged – 'well just go in the other way' – but they should have made that information clear to us, it has to 'live' somewhere. Someone said they had spoken to the management before, but for some reason it just doesn't get heard.

And they are very mechanical and matter-of-fact about it – people mean well in their listening, they think they're hearing you, but… it was in the winter time too, it's just more effort – this wasn't something I was being paid to do, I was trying to support my other colleagues, and surprise! I haven't

been invited back, although it's a group I used to know pretty well.

Acting is an area where people are expected to do everything involved in the interaction of their job, in order to get that job. And that's a common phenomenon for people with disabilities and the film/TV industry is so oblivious, it just makes my stomach turn. And I'm sort of burned out.

One of the people I know in the diversity community wrote a film script and she wanted me to come in and read one of the roles. She had written it for me because that's the only way to get work in this industry. More often than not they'll use an able-bodied actor and just put them in a (wheel)chair.

Graham's Story

Critical Incident? *I said 'but this isn't about studying, this is a massive barrier for my performance, this is not going to end very well.'*

In 2012, I was in a computer science course and the first major component of the course was a weekly assignment, in which we'd have written computer science issues, like a coding issue, and you'd do your assignment on a computer.

I was getting 80s and 90s or more on the assignments, I wasn't finding them difficult at all.

I have a learning disability that affects my working memory, and that's why I tend to gravitate t'ords computers as they kind of work as a prosthetic for my working memory, because it's all

here in a screen or window instead of in my working memory.

So the final exam was worth 40 percent of my mark, it was a lot, and if you failed the exam, then the failure mark you got would be the final mark of the class. It was a little bit scary and the instructor explained that the final exam would be entirely done on paper – and I'm like 'this is a computer science course and you expect me to do the entire exam on paper?'

They said 'yes'.

So they did expect me to do the entire exam on paper. I found this out fairly late in the term. I talked to the prof and I said, 'you know I'm doing incredibly well in this course but if you make me do that exam based on my working memory, given my learning disability, I'm pretty sure I'm going to fail this exam.'

And he said 'well, it shouldn't be a problem, you're doing very well in the course, so if you study you should be fine'. I said 'but this isn't about studying, this is a massive barrier for my performance, this is not going to end very well.'

So I asked if I could have alternative accommodation, and they said no, if they did it would affect the 'educational integrity' for other students. This was in 2012. and I told them this is going to affect the integrity of the course, because for me it is a massive barrier.

We went to the Learning & Disability Centre on campus and they said that for the purposes of academic integrity they weren't able to do anything.

So I wrote the exam. Then I got a call from the course instructor, who was with the professor, and they were incredibly distressed because I had failed the exam – with flying colours! And they were shocked because they had never seen a situation before where a student had gone in with a 78 average and had walked out with a 43 percent mark on the exam. They were saying that, mathematically, if they didn't have the rule 'fail the exam, fail the course' I would have passed the class. But because of that anomalous thing, it wiped out 40 percent of my grade.

They were incredibly distressed and upset, and I said well, you created a barrier, what did you expect, you structured it in such a way that there was no way for me to pass, that's not how my memory works. I mean, taking away my computer is taking away a prosthetic, like making someone run a marathon without a leg and then being shocked that they fail. They get three feet and then they stop.

It was embarrassing for them. I wasn't expecting them to be as upset as they were. I think they believed in merit. It was interesting to me that the professor was actually one of the leaders in computer science field, he has a street named after him in Waterloo, he was one of the first to translate the Oxford English Dictionary into computer language. So I was really interested that this eminent scientist couldn't come up with a novel way to solve that problem [of accommodation to a learning disability].

I went 'over their heads by going to the LDC, who are mandated to follow the AODA, and they upheld the decision of the prof. So my greatest advocate just… when I registered to take the course, the LDC was surprised, I mean, they basically say you shouldn't take math and science classes if you have that kind of learning disability. They encourage you NOT to learn, just pick an area of strength and work within that, rather than seeing that if you engage with the barrier you can shed light on how to change things.

So going to higher authority didn't help – the people who were in charge fell back on the standards of 'academic integrity', the Ivory Tower. Academic integrity trumps even disability accommodation. There wasn't a rethinking of the pedagogical method, no interest in re-examining the problem from a new perspective.

The only thing that changed was that the course instructor said he was willing to give a reference for me.

A lot of my displeasure was focused on the prof – if you're a leader in creating new technology, and you're an educator, the fact that you're not capable of understanding, to not be able to challenge… to think in new ways, just shows your limitations.

I used the example of Stephen Hawking. I said 'what do you think of Stephen Hawking?' and he said 'he's a fantastic, brilliant, intellectual figure'. It is really interesting to see mathematicians and scientists – who are the ones most opposed to giving accommodations — idolize Mr. Hawking because he would never have been able to be where he is now, without those accommodations.

101

John D. Willis

So I said 'I think you should reconsider how you think of people with disabilities.'

John's Story (1)

I am partly blind, and I call myself blind to make it simpler for other people. I started to experience loss of sight when I was a teenager and it became more noticeable to me in my mid-twenties and on into my thirties. Now that I'm 52… I was told, I remember the doctor specifically saying 'you'll be blind by the time you're 40′, and here I am 52, so I always figure… you know, that's pretty useful having some central vision, particularly in one eye.

One thing about it is that the gradual change is difficult for people to negotiate, because I am changing, my sight and my experience of it are changing.

I started with a small firm, set up by a friend, in 1995 – I basically set up a whole section of the company, which is still operating, and so we were quite a successful firm providing services to non-profits – executive consulting and research and strategy type of services, but, you know, for the 'good guys', that's how I always saw it.

So I was pretty senior, sort of equivalent of a V-P if we had been more corporate, and we had about 200 staff, because we ran phone rooms in Canada and in Britain, doing fundraising as well as polling, voter ID, those sort of calls you get from the NDP or the Liberals or Conservatives, for example. So I was fairly well-known in the firm.

About 3 years ago we had a conversation about the need to upgrade all of our software, all of our technology – it had been rigged together on the cheap but we had grown and we really needed to get serious, with really robust enterprise solutions.

So there wee a series of conversations about going to 'cloud computing' in which everyone would log into your computer and there would be a standard desktop and all of the files, all of the back-end, cloud-computing style, would be accessed through an 'intranet'. And I said, okay so we're thinking of sourcing this from so-and-so company, we need to make sure it is accessible, because I'm afraid I'm not going to be able to manipulate exactly how my computer works after we've set up the cloud.

The tech people all said 'yes, of course, we'll take care of that' and in the event, after it was installed, all of my control was taken away – all of my ability to change the colours or make the font larger or change the contrast – I had no way to modify my desktop. It was just a standard desktop that appeared on that day when they switched it over, and I remember saying to someone else in our office 'you know what? I can't use my computer.'

Basically it just took away my access to my computer, which was essentially all my work.

[John's preference for how his computer screen appears]

I figured I could figure something out. But the sense of disappointment was… this is a company that I helped to build, I have a disability that you all know about and yet, still, it was totally meaningless to a whole bunch of people, not just one person. I had raised it and I had put it on the list that I wanted a conversation to check with the supplier, and yet…

So of course I brought it up, I said 'this is not going to work, I need to have more control' and the tech guy said 'well, it *is* accessible but it might not work for you'. So it was as if somehow, in his mind, quote 'it is accessible' which presumably meant the supplier had told him it was accessible, but it was not clear what that really means for a person with a visual impairment.

That really struck home with me: He was not exactly casual about it, but he acted like it was pretty straightforward as if to say that if I would only think about it, I'd realize he's right, that 'it's totally accessible but the problem is it just doesn't work for you'.

So, anyway, I had to go through all sorts of rigmarole and some weeks later I had figured out a workaround –

which was to run most things on my local desktop, in Microsoft Word, so I could get the settings right for me to see the work on the screen but it was cumbersome and slowed me down and meant that I wasn't really sync'd up with my colleagues on the new system.
Basically I had special system, just for me and it was not at all convenient or smooth.

I had a sensation of it being very hurtful, like a relationship broken. I thought we were past this sort of thing, I didn't expect it would happen, so it was kind of part-and-parcel of me deciding to leave the firm. It wasn't the sole cause of it, but I really had started to feel that I was a different kind of fish in this group, then I had an imagination that there was another world I need to be part of, it was part of me deciding to take on a fuller identity as a person with a disability.

So it was about digital tech but more about how an organization communicates with the people involved.

It felt like betrayal, particularly in retrospect, I remember a rising feeling in the weeks afterwards, like 'you know what? this is really pissing me off'.

I still do off-and-on consulting with that firm, but recently we had done a project for a client [a research report [on a professional community] and when the client finally got ready to release it publicly they said 'you know, we'd like to publish it on your [the company's] website because we aren't AODA compliant, and you don't have to be compliant'. I said to my colleagues 'that's total bullshit – even

if it were true that we don't have to be compliant, which is not true, you can't just post something and say 'we posted it here because we don't have to be compliant' – I mean it just violates the whole ethic of the firm, in my opinion. and my colleagues said 'oh, yeah, hm, yeah, whatever' and it sort of just died away and we didn't talk about it.

It is just not happening, it's really unfortunate."

John's Story (2)

On my way to class at the university, running late as usual, I thought I'd get a sandwich at the local Tim's.

I went in, and found the bright orange arrows on the floor that indicate where to lineup. I'm there with the other folks, as you do, waiting in line to order and I looked at the menu - which is a backlit board on the wall behind the service counter. I cannot read it, it is quite bright to me and the lettering disappears because I need to have text that is light on a dark background, not the usual dark-on-light.

I get this feeling of nervousness, sort of a rising anxiety because the line is moving, I am trying to stay in the right spot and not bump into anyone and I'm thinking 'now I'm going to hold everyone up by not knowing what I want to order'. It's sort of a premonition of embarrassment, like 'everyone will be looking at me' and waiting for me to order.

When I got to the front of the line, the server was nice as usual, said 'hi'. I said 'can you tell me what sandwiches you have?' but she did not speak very much English and it confused her, and

I got anxious again about being looked at and holding people up so I'm like 'uh… chicken?' and she brightened up and said 'chicken! crispy?' and from there on the order was set and I had a crispy chicken sandwich for lunch. Pretty good.

But what I wanted was a choice, I wanted to know what my options were, like everyone else who was able to see the menu, and I felt boxed-in and not able to make a real choice. It's just a sandwich, I mean, I'm not trying to make a big deal out of this one incident, but that sort of thing happens to me a lot - sometimes people will try to help but they'll say things like 'do you want chicken? do you want ham?' not realizing that I just want to know the options and decide like everyone else does. And in these fast-food places, that approach of asking me if I want chicken or whatever often seems like a way to make me hurry up and order, so it makes my anxiety worse.

Anyway, I wish they had the menu at the front door, or in a light-on-dark format, or something to help me get the information without going through those negative feelings.

Kazue's Story

Critical Incident? *When I said to the man on the street: "I'll take my chances, it's okay, you don't need to help, but thank you anyway." He was trying to help but it just made me confused and frustrated.*
I want to go anywhere, spur of the moment, like sighted people do. but not seeing makes it very difficult.

I wanted to take a course at Ryerson University. I live downtown and I

chose Ryerson because [name of another university] is so much bigger so it's harder to find my way around it, and Ryerson is much closer to me.

But I did not know that they have different buildings at Ryerson. I just registered for a course, and then when I went it was like 'where is this blasted place?' I didn't know the name of the building, I couldn't find it.

In fact, the building I needed to go to only had the university upstairs, the first floor was another business so even if I was sighted, I might have been confused.

Anyway, I got disoriented, and people started steering me to another place – they think when you're blind that you don't know what you're talking about – 'go this way, why don't you try this, let me take you where you need to go' – stuff like that.

I'm standing at Yonge and Dundas, and I got disoriented, and some sighted people said 'where do you want to go?' and I said 'Ryerson'. They turned me around to head toward Gould St but I wanted to go the other way, south, but by that point I'm disoriented, I'm pointing the wrong way provably and I got upset with the first guy, and I said 'just forget it' and walked away.

Then another person came and tried to tell me how to live my life…

Finally someone with more understanding said 'where do you want to go?' and helped me find the door.

But then, of course I needed to get to the 7th floor, so I had to find the elevator and buttons – when you're with someone they do it for you – then when you get to the right floor you don't actually know where to go. So it took quite a while and it was tiring.

I never had mobility training, my husband taught me what I know. I want to be at many events, doing advocacy as my job means there are lots of events to go to in the evenings, but I can't always get to them – if it's not Mississauga, it's Markham…

You always hate yourself and say: 'Why didn't I get that building name, why didn't I remember the floor number, why did I let other people do it for me?' But you know, is it the Rotman school of business? or Chang? how do I know which business school building it is – there seem to be so many in this city.

And when people see me weaving or hitting things they keep saying 'move to the right, move to the left' – people don't understand that cane users NEED to hit something before changing direction – it even happens at [charity for the blind], when I go to my office I've got to hit the wall and the carpet so I can tell where I am – I had to explain it to another staff

Cane people aren't using it for fashion – we need to hit into something to know where we are. The most dangerous part is crossing the street; before the ATS (audible traffic signal) system I was trained to listen carefully, but that doesn't always work – drivers do things wrong, they rush sometimes, or whatever so it isn't always safe even with a dog.

Sighted people seem to just stand up and say 'I think I'll go somewhere' but for me it always takes a lot of time to plan my travel, I can't be spontaneous like that, there's a lot more work in it.

In the blind community, there's always someone who says 'I go to Mississauga, I go to other countries, what's wrong with you? it's easy' – but I think we're all different, we are not all able to be so mobile. Some people can walk well with a cane, some people can go through airports and train stations and subway stations without any problems, but we are all different and I am not that kind of person. I have a terrible sense of direction, for example.

And then, sighted people want to grab you all the time, they want to steer you – sometimes to the right place, sometimes to the wrong place. If I can get someone to meet me and go from there, fine, but your friends sometimes say 'uh no, I don't want to go to that event' – so I don't go either.

If I just ask on the street, it always happens that people want to say 'no, no, you don't know where you want to go, go this way instead'

Stephanie's Story

When I moved to Toronto, it was with three friends, all of whom identified as able-bodied. The plan was that we were all going to live together – we were all really excited, we're not from Toronto so we were all super-jazzed.

But it turns out, you cannot actually rent an accessible four-bedroom apartment in Toronto – even if you have lots of money. You could buy something and retrofit it but you can't show up with money and rent it anywhere.

We kept making appearances, and we'd say 'we have a friend in a wheelchair' or I'd say 'I use a wheelchair' and people would be like 'oh, there's a co-op down the street that has a one-bedroom' or 'community housing has something' or 'the campus housing might be accessible'.

It was really disappointing to come to Toronto, with our imagination that we're going to be like the girls on *Sex and the City,* and instead….

So we found a house in Parkdale which someone offered to sell to us, but as university students it just wasn't in the cards to get a mortgage. So I ended up moving to housing on campus, while the other women rented a three bedroom walk-up above a cafe at [west end intersection]. It still worked out, they're still my friends and they made their house accessible and I went to all their parties and socially it was okay.

But it was so disappointing, because there's that element of living with someone and now, I guess we're a little bit older and they tell fantastic stories of their time together, things that you can't socially prepare for, that you can't just orchestrate – like for example they watch the Santa Claus Parade from their balcony, and they have no idea that I'm gone. I get to be part of that peripherally because we've decided to make space for me but I

don't get to participate in the things that you can't prepare for, all the stereotypical things that people do when they're roommates.

I had this imagination when I moved to Toronto that I would be in this beautifully accessible city and its been like, I can definitely get around, but living – in that *carpe diem* [seize the day] sort of way is a real challenge. Spontaneity in the city is difficult, whereas in some ways living in a smaller town, where there's not accessibility but there's a sense that we're going to **make** accessibility. There, it's an emergency that you're not at the restaurant, it's an emergency that you're not at the bar – whereas in Toronto the wait staff aren't going to know you or the other people so it's not the same sort of thing, so it's really disappointing that the accessible infrastructure in Toronto is ONLY what's legally required, only enough to make it possible for a disabled person to survive, but not have the full life they may want.

I was really disappointed. It was a rude awakening, at the time and even now I had this picture of myself as this person who would go to school, get a job, and I'd probably buy a house and live in one of the places you see on TV, or places where my friends live. I've become very grateful for the apartment I have, because I recognize there are lots of people living with their parents, living in institutions. I think about that aspect now – I live far away from the cool part of Toronto and I think I'll always live alone, I'll always be childless…

This is a picky point but the retrofitting is so institutional, it's not beautiful

fixtures, it's not 'aestheticized'. It's cold steel grab-bars and massive spaces.

It was the end of this vision of myself, that I'd be this vivacious, successful woman who just happened to be sitting down, and now it's brought about actual anxiety that I won't get everything I want, there's a chance that I may become that impoverished person who's also disabled, that I may become that socially isolated person who's disabled, there's a chance that I may become all the negative social positions that are often attached to disability. and prior to that I was really isolated from that because of the rich community I had so it was intense, it still causes a lot of worry in me, 'what's going to happen?'

Well, accessible housing is fraught… there's not enough of any kind of accessible housing'.

We talked with the university's grassroots 'find a house' service, also the student union has a facility to help people find a rental space but it's not like their boards say 'ACCESSIBLE HOUSING, OVER HERE!' – actually disabled students' experience is really erased from that and what I kept on hearing was the expectation that 'you're going to live on-campus', like 'you should have put your name on a waiting list when you were in high school' – it's a concept of 'secret knowledge' that you should have because you're disabled, the concept that I would have this foresight at age 16 that I would want to go to graduate school in Toronto ten years later.

Sharon's Story

John D. Willis

CRITICAL INCIDENT: *'the minute the driver opens his window and says 'no dogs', all of those feelings just go… that's when it starts: 'Here we go again, I've got to go through this all over again'.*

I was going to a business meeting. I called a cab, I ordered a cab. I didn't tell them I had a [service] dog, I told them I was blind but usually when I tell them I have a dog, it takes forever to get a cab, so I didn't that time.

The cab pulled up and the guy said, 'I'm not taking the dog'. And I said, I explained, you have to, it's part of the law, and he just said 'no dogs'. So I made him wait, while I called the dispatcher to say 'I need to… I mean, this guys got to take me, he's refusing to take me' and then the driver starts saying 'no that's a lie, I'm not refusing to take you – I'm refusing to take your dog'. And I said, 'well the dog didn't call for the taxi and she couldn't care less if she gets in your car, in fact she'd be just as happy to walk. I'm the one that's taking your cab, and the dog is my mobility aid.' So I said the dog doesn't have a right to be in your car, but I have the right to have her with me in the car.

I now need to get to my meeting. and so do I have time to wait for another cab and ignore the situation, or do I battle it out with him? 'I called a cab, you came to pick me up, the law says so-and-so'? I have to decide what I'm going to do.

The feeling is all 'I just want a cab. I just want to go to my meeting, like everybody else.' Why does this seem to be a battle every single time?

Anyway, eventually the dispatch made the guy take me in the car, and in the meantime I'm standing out on the street, people are watching me and I'm embarrassed, I'm running late for meetings, right?

I was angry, irritated, vulnerable, embarrassed. I was frustrated. And I had that sense of 'how often do I have to go through this?'

It happens all the time.

I was lucky that time – this guy actually stopped and said 'no dogs' but most of the time they drive up, they see the dog, and they just drive away and I'm left standing there, not knowing they've come and gone – waiting waiting waiting.

When I call to complain they say 'oh the taxi driver was there, but he said you weren't there so he left' and I can't prove it had anything to do with the dog. If I do get the cab back I feel vulnerable, I mean I'm now captive in the back of their car and they can rip me off, take me to the wrong place, whatever if they're angry at me.

The emotions are frustration, irritation… it's very emotional.

I could be heading to a meeting with the Minister, and if I don't get there… I mean, this could screw up my job, and jobs are hard to get for us [people with disabilities] so I'm going to hold onto it. I get very frustrated…

It's happened before, where I waited four hours for a taxi and missed a meeting with the Mayor – I had to call the Mayor's office and say 'sorry, I couldn't get a taxi to take me'. It's

embarrassing for me – I mean, that's my job, it's not as if I'm just going out for groceries, this is my job.

There's embarrassment, there are other people watching you, I become the focus for people on the sideline. There's a lack of control, and that's what causes all the other feelings.

Tom's Story

I have an invisible disability, in that I'm bi-polar.

I was at [financial institution], I was in the diversity department through AbilityEdge, as a paid intern, on contract. There was a time when I fell into a mixed state, very melancholic and also hypo-manic at the same time, and I wrote a suicide note to my boss – my immediate boss.

And then I went to a conference and I had my phone turned off all day. So she called my phone many times, she was a lawyer, she talked to her boss, who was the Vice-President and even called the police who came over to my home looking for my dead body…

I called my voice mail and got all these messages, and from the Vice-President, her boss.

My immediate boss was super pissed off and said that I would not be hired at the T-D – even though it was in the diversity department – I wasn't fired, but I was definitely terminated before I otherwise would have been. My immediate boss told other people 'do not hire him'.

I talked to the boss, she called me in, and just sort of ragged on me for about an hour, told me what a bad person I was.

I am concerned about being barred from the labour force: will I ever be able to get a job, and hold onto it?

I was definitely thinking about killing myself, but I sent it and then forgot about it, which is part of the hypo-mania, being in a mixed state.

I have a friend who is an employment counselor, who told me 'you shouldn't identify, it's better not to disclose'. So I didn't.

109

Appendix B: Story Capture Protocols

Note: The protocol for the first story capture workshop is contained in the text of

Section 5. In this appendix, readers will find the original protocol for the online

dialogue and for the second workshop (January 31, 2015).

FORUM PROTOCOL/CONTENT
Nov 28 v1

PART I: Story review

1. Review your own and others' stories here [URL to hidden page]
2. Are there any corrections to your story? Additions you'd like to mention?
3. Do you have any thoughts on how your story is similar or different to others? What do you take away from reading all of the stories?
   A. Moderator starts to build a list of key points raised by participants

PART II: SOLUTIONS and RESPONSES

4. What would be a solution to the access barrier you faced?
5. Please comment on at least 2 other stories, what solutions can you think of? (ref by individual names)
6. What NEW KNOWLEDGE are we lacking to pursue these solutions?
7. Who are the other ACTORS, or stakeholders, involved?
8. Can we connect with them easily? Or is it difficult?

PART III: CONNECTING the dots

9. Imagine you had a website, or an easy app on your phone, to post your story to a community, like this forum, where others could help you to
10. Could we use storytelling as a way to generate activism? Your story could be turned into... a PETITION that others could 'sign on to' as a form of public support to your cause
11. Can you see your story as one chapter in a PORTFOLIO of lived experience - story highlights built out of goals, critical incidents, feelings - 'I want to do xyz, this is what I experience, and it makes me

feel abc' for public education or communicating with other stakeholders
12. … or combined with others to create tools for designers and planners, such as:

SECOND WORKSHOP GUIDE – Jan 31 Workshop (OCADU)

Content in the Invitation:

● Whereas the main focus of the first workshop was on telling stories about past accessibility experiences, [POST ON WALL:] the purpose of this second workshop is to share ideas about how things could be changed for the better in our personal, and collective, future. we'll talk about
  ○ sharing our stories in a community of storytellers
  ○ making concrete change with regard to accessibility
  ○ helping each other succeed

● no right/wrong answers - this is co-creation, your process is independent of my intentions

● Since we first gathered to tell stories at the first workshop, have you thought about accessibility challenges in a different way? How so?

● Please think about whether you've had any noteworthy experiences, positive or negative, that you'd care to share at the next workshop.

Recording: Remind participants that the session is videotaped and audiotaped.

Materials: Each participant will have a hardcopy of the stories so far, and be given the journeymaps for Sam and David's story. Index cards, masking tape, post-its, chalk, whiteboard markers. Video camera and digital recorder.

Appendix C: Story Structure & Representations in Service Design Tools

| Structure Component	Denotes	Representative Quote
SELF-IDENTITY	Statements about who the teller believes themselves to be, how they 'see' themselves and others through the lens of belief and attitude	"I was tired of feeling like a burden on my family. I wanted to have a job... I wanted to pay my own tuition and support myself because my mother doesn't make that much money and I believe in being independent
		"I want to be able to go anywhere, spur of the moment, like sighted people do."
GOAL/ASPIRATION	Statements about what the teller was trying to achieve when they encountered a barrier; the psychic 'setting' for the story	I'm an actor, and I wanted to connect with people in the industry."
		"When I moved to Toronto, it was with three friends, all of whom identified as able-bodied. The plan was that we were all going to live together - we were all really excited to come to Toronto,"
PLACES & THINGS	The *where* and *what* of the events - physical or digital setting(s)	"When I tried to go into the restaurant, I went to the main entrance and there was this huge step, and these big doors and no apparent other access... I was taking a photo of the door and the step to show there was no access..."

Structure Component	Denotes	Representative Quote
SEQUENCE OF EVENTS	Description of *what happened*, often specifying objects, actions, and processes in which the teller was engaged	"The cab pulled up and the guy said, 'I'm not taking the dog'. And I said, you have to, it's part of the law, and he just said 'no dogs'."
PEOPLE	Descriptions of other people in the story, through the lens of tellers' understanding of the other's attitudes and beliefs	"We talked with the university's grassroots 'find a house' service, but it's not like their boards say 'ACCESSIBLE HOUSING, OVER HERE!'"
		I said, 'you know, I'm doing incredibly well in this course but if you make me do that exam, given my learning disability, I'm pretty sure I'm going to fail this exam. They were incredibly distressed and upset, and I said 'well, you created a barrier - what did you expect?"
FEELINGS	Statements about the emotional and psychic reaction of the teller, and/or of other players in the story	"It was the end of this vision of myself, that I'd be this vivacious, successful woman who just happened to be sitting down, and it brought about a real anxiety...""
		" I had a sensation of it being very hurtful, like a relationship broken. I didn't expect it would happen, so it was kind of part-and-parcel of me deciding to leave the firm... I had an imagination that there was another world I needed to be part of...

Structure Component	Denotes	Representative Quote
		deciding to take on a fuller identity as a person with a disability."
WISHES	initial reflections on what the teller 'wishes' had happened instead, often with reference to feelings more than to specific 'solutions'	"...if another professor, or someone with a computer science background, had gone in there and made my case it would have made a difference."
POSSIBLE SOLUTIONS	Descriptions of specific system, product, or service changes that could reduce barriers.	"Taxi companies need to make a strong and binding policy that they take seriously and enforce, that requires all of their drivers to sign a document that indicates their understanding of the rules on requiring them to take people with their guide or service animals." [from online dialogue]
NEW FUTURES	'What if?' scenarios, often phrased in the negative register, as if no solution will occur (expressing fear rather than hope).	"I am concerned about being barred from the labour force: will I ever be able to get a job, and hold onto it."

Figure 10: Representing Story as Service Action Sequence
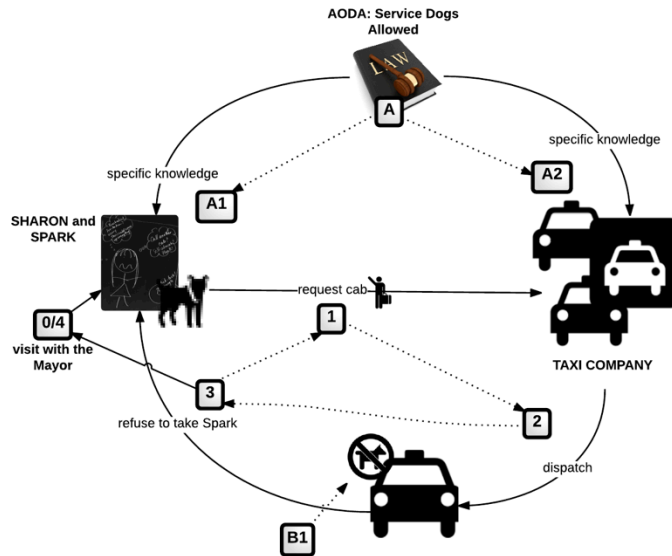
Sharon's story represented as an action-sequence: 0. Sharon has an appointment with the Mayor 1. Diane calls for a taxi 2. Taxi co. dispatches cab 3. Cab comes but refuses to accept Spark, Sharon's service dog 4. Sharon cannot get to the meeting with Mayor on time. There is a separate 'knowledge-sequence' - A. the existence of the AODA reg that requires all taxis to accept service dogs, knowledge that is possessed by Sharon (A1) and the taxi co. (A2). The AODA is 'environmental' knowledge, that is, part of the overall environmental conditions in which the unique action-sequence of Sharon's cab experience exists. Service-dominant logic treats this type of information or knowledge as inherent to the service co-creation (Vargo, et. al. 2008). The cab driver is affected by another type of environmental information - cultural-religious view that dogs may not be brought into his cab (B1). Using Glushko's (2010) definition of 'service system contexts', this system would be categorized as *Person-to-Person Technology-Enabled,* but it is in breakdown because specific knowledge of how the AODA works as an input to the service co-creation is not held by one of the actors - the cabbie.
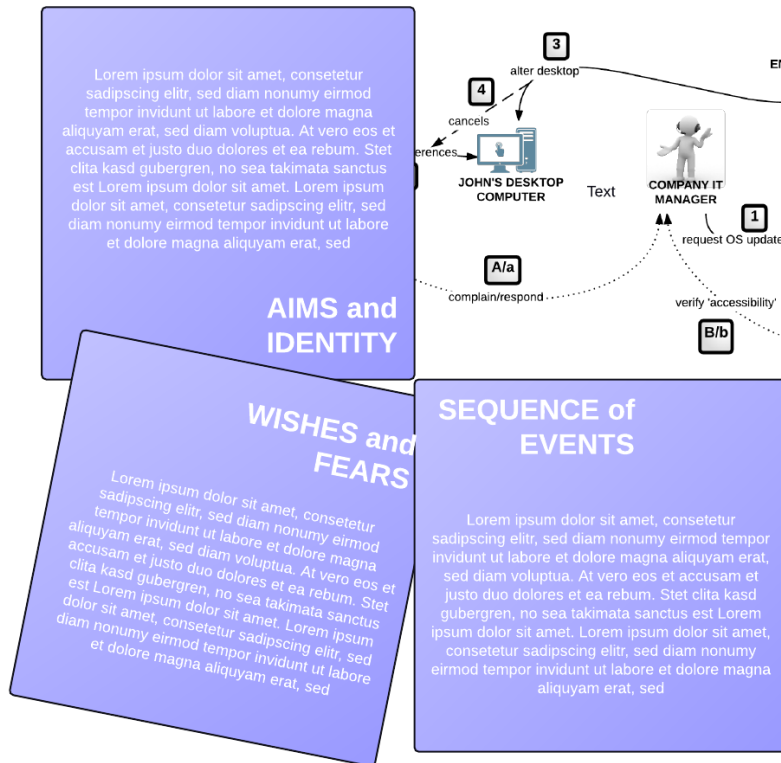
Figure 11: Using a Quad Chart to Communicate a Story – Maintaining the richness of a story when communicating within and between design teams may be feasible with the use of quad charts, such as this mock-up based on the story components analysis starting on page 112. A tool like this can be varied by users to suit their needs, and could work well in both online and offline contexts.

Appendix D: AccessMakers Modules

The following pages show the AccessMakers modules as they were prototyped in

Google Drive, and shown to reviewers. All of the references cited here have been

relocated to the main document reference section, starting on page 89

1 Why Be Inclusive?

I want you to join AccessMakers, a community and a method to make your
organization more inclusive of people with disabilities - and, at the same time,
help you deliver on your mission more creatively.

But… why be inclusive?

Inclusion is about deepening your relationship with the people who matter - your
customers, your clients, your employees, suppliers, partners (and other
stakeholders too). It takes different forms for different organizations, but there are
some common themes emerging from theory and practice:

- Inclusive organizations tap the creativity of their whole 'ecosystem' so
  they are better able to exceed customer/client expectations, grow their
  markets, and achieve better outcomes overall.
- They have employees who feel happier and more productive because
  they are part of a responsive, creative workplace.
- They foresee major challenges and find better solutions because they
  have more points of view informing their strategic decisions.
- They create shared value with all of their many stakeholders, so they are
  more sustainable and resilient than traditional organizations.

When the perspectives of customers or clients are included in your design
process right from the start, product and service innovation is more likely, and
more likely to succeed. T-D Bank, Best Buy, Barclays, IBM, and many local
governments know this and are practising it every day.

This means going beyond market research and satisfaction surveys, to integrate
diverse individuals right at the start of development and retaining them

throughout the innovation cycle. Inclusive designers call these people 'edge cases' (i.e. they are not the 'average user' but rather, the outlier) and we think they are a key to unlocking creativity.

But the silos and power-centres of many organizations sometimes work against bringing new voices and perspectives into the dialogue - not because people don't believe in diversity, but just because old habits die hard.

And because of this inertia, *diversity alone is not enough.* Diversity does create new value - this much is widely acknowledged - but researchers working with firms all over the world have found that the key to mobilizing that value is *inclusive leadership* - leaders who openly support difference, and who encourage people to speak up with a wide range of concerns and new ideas.

AccessMakers is a comprehensive method for bringing new viewpoints into your organization - the lived experience of people with disabilities, and anyone who experiences access barriers with respect to your services, products, workplace or organization. It is designed to 'bring the outside in', in productive way that respects all the points of view in your existing structure and builds an inclusive leadership style for the future.

AccessMakers should give you new insights into many different specific parts of your value-chain or service delivery model and highlight new thinking that can lead in truly innovative directions. It aims to empower people who are often excluded or whose stories are not heard - in a way that can benefit your organization.

When fully developed AccessMakers will be an integrated platform that includes

- An easy method (similar to focus groups) for collecting stories from your stakeholders who experience access barriers, and guidance on how to integrate these new perspectives with the knowledge you already have in your organization.
- A flexible set of human-centred design approaches to guide you in framing the problems, developing solutions, and spreading the benefits to your wider community.
- An online community providing independent customer/client feedback on your access challenges, and peer support from others who've faced challenges similar to yours

- A shareable digital portfolio to keep track of your projects, methods, and progress toward inclusive innovation.

NEXT: [Access to what, exactly?](#)

PREVIOUS: [Why be inclusive?](#)

2 Access to what, exactly?

AccessMakers is an inclusive innovation method that uses people's direct experience of accessibility challenges to uncover opportunities for positive change in design, markets, services and policies.

By bringing rich, lived experience of real people directly into your design, development, or program planning, AccessMakers goes beyond checklists to help you do a better job meeting the needs of customers, clients, employees and others in your community with disabilities. At the same time, it will help you develop an inclusive leadership style and unlock innovation in your process, products, services, networks and customer experience.

It's for:

- organizations or agencies that want to bring diverse life experiences to bear on their own innovation cycle
- Individuals who want to engage in collaborative projects that remove access barriers and build community focus on inclusive design.

Access to life

Many of us think of 'accessibility' as bigger doorways, entrance ramps, screen-readers and grab-bars in washrooms. These things are nothing more than modified interfaces and 'affordances' created to compensate for a mismatch between what's been designed (places, products, services, systems) and the functional abilities of some people. These modifications are often treated as

'exceptions' and they become an afterthought - people with disabilities who helped to create these Modules told many stories of hearing 'sorry' as they were told the documents weren't available in alternate format, the ramp wasn't yet installed, the app isn't coded for access by screen readers...

One way of changing the frame around access is to notice that what people want access **to** are the same goals or tasks that we all pursue at one time or another in our lives - caring for family members, doing their best on-the-job, and having choices about learning new skills and participating with others. Accessibility is good design, restoring a positive sense of 'flow' between a person, or people, and whatever they want to do with their life - same thing we all want.

EXAMPLE: Can using an ATM be 'delightful'? In this first-person narrative, the character creates a richly-textured sense of how it feels to encounter the innovation that removed access barriers for them. They only mention the *interface* in passing ('delightfully clear and smooth audio interaction') but their feelings, priority on family, and sense of transformation are in the foreground.

"Last Friday, I used an ATM at the Barclays [Bank] opposite King's Cross station. What I experienced (apart from a delightfully clear and smooth audio interaction with the machine through my ear-phones) is hard to put into words… but I walked away from the machine feeling 15 years younger!

I realise the last time I must have used a cash machine, without the anxiety and hassle that has become normal to me, and as a sighted person, was 15 years ago.

The fact that Barclays cash machines are becoming accessible once again… is recreating a new wave of optimism about just going out, with my two very young children, and being able to do normal things like this, I really cannot thank you enough for what you've done."

(Barclay's customer, November 2012, quoted in: Talent Innovation Taskforce, 2014)

The business case

What people are pursuing in life may well be precisely what your organization provides. Access barriers are essentially poor design that stands in the way of the value you've spent so much talent and time to create - whether it is a service,

a product, or a place. And if customers or clients have a substandard experience of the value you're trying to deliver, they won't pass on positive impressions to their family and friends, or want to come back for more. . You've lost not only an individual from your community; you will likely have lost their network as well. (Helkkula, 2012)

The initial research for AccessMakers involved a storytelling group of eight people with disabilities including one man with a mental illness, one with a cognitive disability, two women who use wheelchairs for mobility, two low-vision individuals, and two women who are profoundly blind. Through their experiences, I was able to understand access in the following ways:

- People with disabilities mostly don't complain - they 'self-accommodate', which means they figure out a 'work around' to many of the barriers they face daily. But work arounds cause fatigue after a while. Just try planning a trip on public transit if you're in a wheelchair - so often this path leads to self-exclusion. Yin, a young blind woman, told us she doesn't attend many career- and job-oriented networking events because they require travelling at night.
- Work arounds also mostly only meet immediate, minimal needs. What people need are seamless solutions that enable them to be productive and independent, which human factors specialists call 'effective need'. For example, Rosie started work in a call-centre where there was no accommodation for her low-vision. She self-accommodated by propping up her keyboard and putting her nose to the monitor to read her script, but this was only feasible for a couple of weeks and, as her productivity fell, she was let go. You can walk across the room to read a screen to a blind colleague, but they really need to be able to access and manipulate digital information at-will (like everyone else).
- Self-accommodation doesn't always work. George wasn't allowed to take his university exam on computer, so he failed, and flunked a course in which he'd been averaging 80+ percent. This simple lack of an accommodation harmed his career - not to mention his self-esteem.
- Because people with disabilities self-accommodate so much of the time, it's often assumed they have 'special knowledge' of how to solve their problems in every situation - where to find accessible housing, or the ramped-entrance hidden in a building next door, or how to make software work on every platform. This assumption is an added burden, a 'secondary disability' because it often

means that others can excuse themselves from knowing how to accommodate people with disabilities.

- That very lack of knowledge by others can also become the primary barrier - for example, when a taxi driver refused to take a woman's service dog, causing her to miss her business meeting with the Mayor of her city. She knew that the law was on her side but the driver didn't, and she did not have the time or resources to correct the situation in the moment.

People experience very strong emotions when these events happen, including anger, a sense of betrayal, and diminished expectations for their future ability to remain independent. 'Maybe I won't ever be able to hold a job', one well-educated and presentable young man said.

Making things more accessible, then, means preserving the dignity and independence of our colleagues, customers, clients and friends. It means taking some of the burden of 'shadow work' off them, so that they can pursue their life goals without being excluded. It is about restoring the sense of the positive 'flow' to life. Making better access is not about meeting minimal needs, but rather it's about letting everyone be productive and fulfilled in the ways they choose.

Why Stories Matter

We need storytelling to help us keep our focus on the human dimension with which we all empathize - the goals and desires of daily life that are expressed by the storyteller - rather than giving away the role of protagonist to the inert interfaces that should (literally) have a supporting role.
http://goo.gl/forms/jhWWxFlJUS

NEXT: Discovery Through Storytelling

3 Discovery Through Storytelling

> *"We make deeper connections with people when we reveal our humanity and speak in ways that people find real, and natural."* (Williams-Ng, 2013)

When we gather to try to work together for inclusion, it's important to be able to see things through others' eyes - especially the eyes (or ears) of those who experience exclusion, people who are our 'edge cases'.

Designers often use what are called 'personas' - detailed and colourful descriptions of the people they are designing for - to 'stand in' for real people (cf. Step Two Designs, 20004). This methodology has been criticized for giving a "cloak of smug customer-centricity" (Portigal, 2008) while actually distancing designers from real people who can benefit from, or be put at risk by, their work.

This is a critical hazard in inclusive design, where the 'users' we are interested in are, by definition, 'edge cases' and therefore people whose life experience may not be shared by a typical designer. Maybe this is inconsequential for a few luxury goods, but when it comes to inclusion we need to make sure the process itself is inclusive, or we risk missing the mark in our outcomes and impact - that's why AccessMakers is so valuable because it is fundamentally a story creation method.

Stories are an invaluable tool for communicating personal experiences, encapsulating information as well as feelings about the world that an individual inhabits. They help us empathize deeply because, when we watch someone tell a story, we see the 'echo' of how they act in their world - not just how they think or talk.

But stories are also vessels for more 'objective' types of data - critical incidents that reveal flaws in the design of places, services and products. Thus they serve many people's needs at once - architects and engineers, designers and developers, people with disabilities, service agencies, retailers, managers, policy-makers and regulators...

Who to include: This workshop module is intended to engage 8-12 individuals who are experiencing barriers with respect to your organization, - ideally, include

employees as well as customers/clients because these cross-perspectives can be very creative.

These individuals can be recruited from your employee, customer or client lists (as you would for a focus group) or through your complaints system (or the AccessMakers online community - more below).

You should also include other people as observers and co-facilitators, provided they are the minority. People who are responsible for inclusion, ICT, product design, service delivery, monitoring, quality assurance, innovation, and/or customer/client engagement are likely to find this workshop very interesting as they will likely be involved in the subsequent steps.

Invitation: Participants are invited to reflect on personal experiences or incidents related to accessibility in your organization or with respect to your products and services. Let them know that you are also inviting people in your organization to participate who want to learn about making positive change.

A. Story Creation

Arrangement: Small groups of comfortable seating, which can be easily arranged into face-to-face pairs and foursomes. Provide some tables or open floor space for drawing and ask participants to turn off unnecessary devices.

Have on hand: flipchart pad with coloured markers and large post-it notes for each group of storytellers.

Make sure there is food and drink, and let people move around to create their own sense of how the space should be used.

Distribution of Participation: This part of the workshop is based on the '1-2-4-All' style used in *Liberating Structures* (www.liberatingstructures.org) - starting the storytelling alone, then work in pairs or foursomes (depending on the size of your group) and finally as a whole group.

Sequence:

1. (1 min) Ask individuals to reflect, silently on their own, on any accessibility challenge they have faced, with respect to your organization's services, products, places, or processes – how did that challenge manifest itself? (1 min)

2. (40 min) Form groups of 2s or 4s and ask each individual, in turn, to share their story. Listeners should adopt a non-judgemental stance. When the teller is finished, listeners should ask for clarification of the narrative and its details until each is comfortable that they know about:

- Where did the story take place?
- What happened?
- Who was involved?
- What goal or aim was the individual trying to pursue when they encountered the barrier?
- What feelings were evoked, either for the teller or for others? Think about whether the TELLER is also the PROTAGONIST (the one to whom the story matters most) - this is not always the same person!

Link to ACCESSMAKERS EXAMPLE STORIES

3. Give each group an assistant to sketch the 'journey' of the storyteller from the start of the story to the conclusion. This can be very 'sketchy' but try to capture people, things, flows, words, imagery, and metaphors as you go. Here is an example from previous work (it includes Santa Claus in a story about finding an accessible house!).

4. (20 min) For each group, add a service provider/designer from your organization to lead this segment (this can be the sketch artist from the previous step).

Usually when someone tells a story about encountering a barrier to their chosen goal, it will surface fears/concerns about their future and these will relate back to their self-identity - 'I might never be able to hold a job'; 'will I be allowed to study what I want, or just what the system says I can handle?'; 'I have this vision of myself living in poverty...' To help people move to a more creative place, at the conclusion of each story ask the original storyteller to:

- Give some thoughts about how to remove or change the barrier that they experienced. Discourage self-blame ('I should have...') and encourage system thinking.
- Draw these thoughts next to the journey map - preferably do a NEW journey in which the barrier is removed. Let others chime in.
- Identify a 'critical incident' in the story - that is, a moment that they feel best expresses the total meaning of the story (or has the most impact for them as the one who experienced it). Write out the critical moment on the sketch paper alongside the journey map.

5. (30 min) All together: Telling stories is an experience in its own right so it's important to give participants time to reflect on what they've heard, said, and learned. It will enrich your process. During this phase of the workshop, the conversation can be self-organized by participants but make sure everyone who told a story gets a chance to contribute to the reflection.

John D. Willis

B. Sharing in a Fishbowl (60 min)

If you are comfortable working together with the storytelling participants, it is best to move straight into this exercise because your impressions are fresh and you have the participants there to give your team further insight. However, it can also be moved into **Module 4: Knowledge & Trust** (link below) with some adjustments.

Arrangement: An informal circle-within-a-circle. Storytellers on the outside.

Have on hand a black-/whiteboard, post-it notes.

Distribution of Participation: This exercise is an opportunity for the designers, developers, managers who were observers in the Storytelling segment to share their learning. You will probably find that, having listened to a number of personal stories from their customers/clients/colleagues, people will be open and honest in this exercise, but the moderator needs to be supportive of disclosure (e.g. if a manager wants to acknowledge their own limitations) and ensures dialogue is wide-ranging and comprehensive.

Sequence:

(45 min) FISH: Take turns around the circle 'downloading' your learning from the storytelling session (or the stories as posted/distributed).

1. Each person puts all key information that they want to share on Post-its, and uses them to describe who you met, what you saw, the facts or concepts you gathered, and your impressions of the experience.
2. Cluster the Post-its together as you put them on the wall or on a board so that you have a record of your discussion. (You'll find they tend to cluster into data about users, data about barriers/interfaces, and data about new thoughts or unresolved questions from your team.)
3. Encourage participants ('fish' that is) to pay close attention and to feel free to ask questions if something isn't clear.
4. This process is best done right after the Story Creation process while people's perceptions are fresh.

(20 min) BOWL: Let the storytellers form a 'fishbowl' outside the main circle, and ask them to remain quiet until the 'fish' have finished their work.

1. Then give the outer circle a chance to reflect back to the core group any thoughts or reflections they may have. Capture these as well on your board and in your notes. This will help you complete an initial synthesis of the day's findings.

2. Make sure to document what's emerged on the board, and add it your Story Portfolio.

What to do next

Make sure to keep all the drawings and notes from both parts of this Module (stories and fishbowl), and to transcribe the audio so that you have a full-captured story from each participant.

Review the stories before moving forward, taking note of:
- How do individuals describe themselves and their aims? How does this person relate to your organization? (These can help you build PERSONAS and USE CASES.)
- What was the SETTING for the experiences described? What interfaces are experienced as barriers (digital systems, physical locations, etc.) - do your team members view the setting differently?
- What was the sequence of events in real-life, but also in the ideal alternative future? What did your team add or modify about the sequence in their fishbowl?
- What FEELINGS were encountered, and by whom? What metaphors and imagery did the storyteller use?
- List the critical incidents, to give you short, memorable labels to remember the stories by and communicate them more widely in your team.
- What SURPRISED your team members?
- How did storytellers' perceptions change when they heard discussion by the team?

The stories are your 'edge cases' and they tell you a lot about the settings and scenarios for your innovation process, so all of the information contained there will be useful.

AccessMakers is also an online community that offers digital support for your story creation. Open a Portfolio, share and learn at AccessMakers.org **[links to prototype pages]**

NEXT: Knowledge & Trust

John D. Willis

PREVIOUS: [Discovery Through Storytelling](#)

4 Knowledge & Trust

Now that you have a clutch of real-life stories and the first cut at your new learning as a team, this Module helps you frame specific challenges that you want to work on resolving.

These frames need to be specific enough to engage your team in concrete accessibility improvements, but holistic enough to spur creative problem-solving that drives your mission forward. The objective in this workshop is to identify the point where accessibility and inclusion drive meaningful innovation on a broader scale.

This will require the best from your existing skill-sets, but might require new skills to be developed. Culture and habit play a big role in every organization, so DO NOT SKIP THIS STEP! If you do, the 'silos' will dominate the whole process and the idea here is to loosen up those boundaries in a way that people will find safe and respectful.

Who to include: Cross-departmental teams are best - this is not meant to be done only by the people with the title 'accessibility coordinator'. Take a cue from the stories you gathered and broaden participation as much as you can, with a mix of functional specialists (e.g. developers, designers, ICT, etc.) and managers, planners and coordinators. Take people from your frontline (near the interface with customers and clients) as well as those who work 'back stage'. Also consider involving your (external) consulting designers and planners - again, do not limit yourself to people with 'accessibility' in their job title - innovation is a creative process so lowering barriers is definitely good!)

Invitation: Ask your participants to review the stories collected in the previous Module, either online or on paper. Also ask them to reflect ahead of the workshop on examples of successful interventions to resolve accessibility challenges that they are aware of – who was involved, what can we learn, and why did it succeed?

Arrangement: Break into mixed groups of 4-5 people. Give each group one or more of the stories created in the previous workshop, as a structured summary

(see 'what to do next' under the Discovery Through Storytelling module), and a flipchart or notebook to keep track of their findings.

Distribution of Participation: Small group work followed by a full group report-back.

A. Framing Inclusive Challenges

Sequence: (40 min) Framing problems as part of the creative process is not about assigning blame. The keynote in this exercise is to work on framing problems in a way that does not make anyone feel defensive about past work that's been done.

1. Based on the stories and what the group has learned (see previous exercise) start by writing down the problem that you're trying to solve. Then rephrase it as a *'How Might We...'* question and assess whether it feels either too broad or too narrow.

2. Now, ask your team these three questions:

    a. Is my question focused on ultimate impact? Keep in mind, we're trying to meet 'effective needs' - what a person needs in order to be productive and independent as they pursue their ultimate aims
    b. Does our (rephrased) question allow for a variety of solutions? This is not the time to try to settle on 'the' solution - seeking innovation is an iterative process so for now, try to keep multiple approaches in play (this will help to meet multiple needs, rather than 'special needs' only)
    c. Does my question take into account constraints and context? The individual who tells a story has a specific context and constraints - can they find the right information to access your services? Are they countering your organization out of choice or necessity? - But you also have your own internal context as a team, agency, or company: think about how they change your problem definition.

3. Try rephrasing your '*How Might We..?'* question, taking impact, variety of solutions, and constraints and context into account. Write it down.

129

4. Repeat steps 2 and 3 and keep going until the question feels neither too narrow nor too broad and hits the three criteria laid out in step Two.

EXAMPLE: Taking John's sandwich-buying experience from the previous module as our guide, this exercise might produce the following 'How Might We...' frames:

- … make our locations a magnet for customers with disabilities?
- … provide menus and ordering information in multiple formats (not only menu boards) for customers with various presentation preferences?
- … make it possible for all customers to order from anywhere in a location, without having to line up to order?
- … give all customers access to menu information regardless of their functional limitations?

Note that none of these problem frames are about 'special' treatment of people with different abilities (that might be necessary in some circumstances, but don't start with that mindset or you'll miss the innovation potential!)

B. Making Progress Together (45 min)

Sequence:

- Bring all groups back together and share findings by showing their work. Allow for questions and feedback on each group's work.

- The Moderator/facilitator should guide with these (and similar) reflection questions:

- Tell us about how you framed the problem as a team. Did diverse views (e.g. skill sets, organizational position, authority, past experience…) come out in the discussion? Was that a positive factor, or a difficulty?
- What constraints and context did you consider?
- Do the new problem statements challenge our existing skills, silos, and ways of doing things? In what ways?
- How important is the timescale for solving the problem (some challenges take a long time to resolve - what can we do in the short-run?)

- What new knowledge do you feel you need to gain, or new skills develop?
- What are the most significant success stories in our organization? What happened, what can we learn? How do we know it was a success?

Summarize findings in a set of flipchart notes or clustered post-its before closing. Encourage group members to sort the emerging problem frames ('how might we..?' statements) in whatever way makes sense to them - once you have the group's feedback on the reflection questions above, it may take a few iterations to find a sorting scheme that fits your context and organizational culture. Let it take the time it takes. Sort order might be:

- short vs long term
- physical, digital, hybrid problems
- frames that fit existing innovation projects vs those that may need new support
- problems with perceived direct ROI vs those with less direct ROI

Be sure to tag the 'how might we..?' statements with the name of the original storyteller(s) whose experience inspired it AND with the team members who worked it up into a frame.

The next Module will help you develop your options for action.

NEXT: Innovation & Inclusion

PREVIOUS: Knowledge & Trust

5 Innovation for Inclusion

By the time you reach this module, you should have:

- A Portfolio of real-life stories reflecting actual users of your services, products or systems, annotated with new learning and reflections by your team (NOTE: you can set up your Portfolio on www.accessmakers.org, to receive input from the wider online community of citizens/customers/clients, employees, or other stakeholders

John D. Willis

- A set of impactful problem-frames ('how might we..?') that are open to multiple solutions and are sensitive to AND challenging to your context
- Feedback from your team about how your existing skills and processes may need to be supplemented or re-organized

In other words, you should be feeling the effects of bringing the perspectives of 'edge cases' into your thinking! But of course, your organization already has methods and processes for reviewing what you do and making change. This module will help you take the step from *discovering, sharing* and *framing* to *making* by giving you methods for synthesizing and telling new stories that will provide the springboard for change.

Use it in combination with your existing way of doing things and be sure to engage real storytellers in the evaluation process.

Who to Involve: This works best when people experiencing barriers are invited along with a diverse team of managers, designers, planners, developers, managers, etc. who are responsible for different functions in your organization (same invite list as the *Discovery Through Storytelling Module*).

Invitation: Invite participants to explore the questions that you identified in the 'how might we..?' exercise (previous module) - specifically "what kind of help do you need in order to address this challenge?" and "what's it like to live in a world where this challenge is resolved?"

Materials: Have the problem-frames ('how might we..?' statements) posted on the walls and available for review ahead of time for all participants. They need to be familiar with them, so let people circulate and review for 15-20 minutes before starting the session. ``

A. Troika Consulting

Derived from a technique in *Liberating Structures* (McCandless & Lipmanowicz, 2012), this is a great way for multidisciplinary groups to seek solutions together and work across boundaries. It helps individuals recognize others' unique knowledge and skill, and have theirs recognized in turn.

Arrangement: Any number of small groups of 3 chairs, knee-to-knee seating preferred. No table and no devices!

Each group should have one storyteller (person with access challenges) and the other two should not have identical functional roles in your organization - diversity is key here.

How Participation Is Distributed: In each round, one participant is the "client," the others "consultants" (NOT distinguishing between people with disabilities and your other team members). Everyone has an equal opportunity to receive and give coaching.

Sequence:

(15 min/round or 45 min total)

> Invite participants to choose one of the 'how might we..?' questions they want advice on (that they will ask about) when they are the client)
> Groups have first client share his or her question. (1 min)
> Client turns around with his or her back facing the consultants. Together, the consultants generate ideas, suggestions, coaching advice, possible solutions to the problem. These do not have to be 'full solutions' - they can be approaches and strategies, design process ideas, or ways of prototyping - as well as 'solutions' (4-5 min)
> Client turns around and shares what was most valuable about the experience. 2-3 min.
> Groups switch to next person and repeat steps.

Ask each group to capture key points from each round, in jot notes for later collation and review.

B. New Stories (Scenario Building) (2 hrs)

Each team of three now has 1, 2, or 3 open-ended problem-frames ('how might we..?' questions) PLUS a collection of solution-oriented statements for each, generated in the Troika Consulting exercise (above).

Now it's time to try synthesizing all of this by using made-up stories. Christine Bold, in her book **Using Narrative in Research** (2011) notes that story-making helps us "to make sense of diverse realistic data through analyzing the parts and then synthesizing them into… a narrative that is readable and meaningful" [in a given community]. In our case, the new stories must be 'meaningful' to all

133

participants including people with disabilities who have real-life experience of access barriers.

Storytelling is also a great method for understanding the innovation 'space' and/or to evaluating prototypes, particularly if they relate to services or customer/client experience. Innovation expert Hugh Dubberly says that "explaining a model involves telling a story, navigating a path through the model. Similarly, telling a story builds a model of actors and their relationships in the mind of the listener." (Dubberly, 2008)

The purpose of this final part of the AccessMakers method is to tell NEW stories that highlight positive approaches to the twin constraints you've been working within: On the one hand, we need to make specific things or services or places more accessible for the original storytellers, and, at the same time, generate innovation that serves the needs of other stakeholders (including the company or agency sponsoring these workshops).

So it's not enough to say 'the blind patron was helped by having a shop assistant read the price tag to her'.

This exercise ends with a reverse-fishbowl (see *Discovery Through Storytelling* module) - this time, the people with disabilities reflect on the stories that are being told about possible futures.

How Participation is Distributed: Each person brings the same problem-frame to the table that they worked with in the previous exercise, and the team of 3 works collaboratively in this exercise.

Sequence: With the new knowledge of the problem-frame that was generated in the previous exercise, team members work on three stories (one for each problem-frame chosen by individual members).

- Tell a short story about the protagonist of each scenario - this person can be fictional, but they should be a character that has experienced one or more of the access barriers described in your Story Portfolio (see *Discovery Through Storytelling* module).

- Using your specialized knowledge and the sharing you've done in the previous exercise ('Troika Consulting'), develop a scenario in which

you've changed their situation so they can pursue their aims without encountering access barriers.

- Keep working over the form and content of the story until you have, at a minimum:

  Who they are in their own words, their **SELF-IDENTITY**
  The **ACCESS BARRIERS** they've experienced relative to your organization
  Their **AIMS, or GOALS** at the time of your scenario/experience
  The **SETTING,** and any **THINGS** or **SERVICES** you want to deploy to meet this individual's needs
  The **SEQUENCE OF EVENTS**
  Any products or services or systems
  The **PEOPLE** or other **CHARACTERS** involved
  Descriptions of their (and others') **FEELINGS and EMOTIONS**

- As you develop your scenario (synthesize), use a table like this to keep track of specific needs for making this scenario real (analysis):

Success Factor to Make the Scenario Real	What We Have	What We Need
Skills/talent *what you can do as a team and individually across your organization, to make the scenario real*	*(got it)*	*(need it)*
Resources *the time, knowledge, licenses, code, physical plant, authority, or other resources needed*	*(got it)*	*(need it)*
Structures & Processes *Methods, procedures, decision-techniques, or development cycles needed*	*(got it)*	*(need it)*

- When all groups have had time to develop their scenarios, share them in a large group. Ask the original storytellers (people with disabilities) to offer reflections on what they have seen and learned through working with the rest of their team(s).

What To Do Next

Iterate! (do it again!!)

And join the AccessMakers online community (Digital Supports & Online Community page) to compare your learning, ask for help, and find out more about how people with disabilities are driving innovation in other organizations

As projects emerge, consider these questions:

- Who ELSE can benefit from this project? In what ways? How can you test and evaluate these possibilities?
- How can you measure progress toward inclusion? How do we measure innovation?
- Is the focus of innovation on (answering this will help you set up appropriate teams, and crystallize the ROI over time)
    - customer experience?
    - core processes (how you make value)?
    - new or modified products or services?
    - platforms, networks, alliances, partnerships?
- How will the original storyteller(s) stay engaged with you? They did part of the work, after all, so they deserve feedback and the reward of seeing your project succeed. (We have a suggestion, further on in this Module.)

NEXT: Digital Supports & Online Community

PREVIOUS: Innovation & Inclusion

6: Digital Support and Online Community

AccessMakers is all about making connections between people who have daily experience of access barriers and people who can help resolve them. Face-to-face storytelling creates trust, the will to share knowledge, and motivation for action - but the tools of online community can support collaborators in many important ways, and make it possible for far more people to participate in what you're creating.
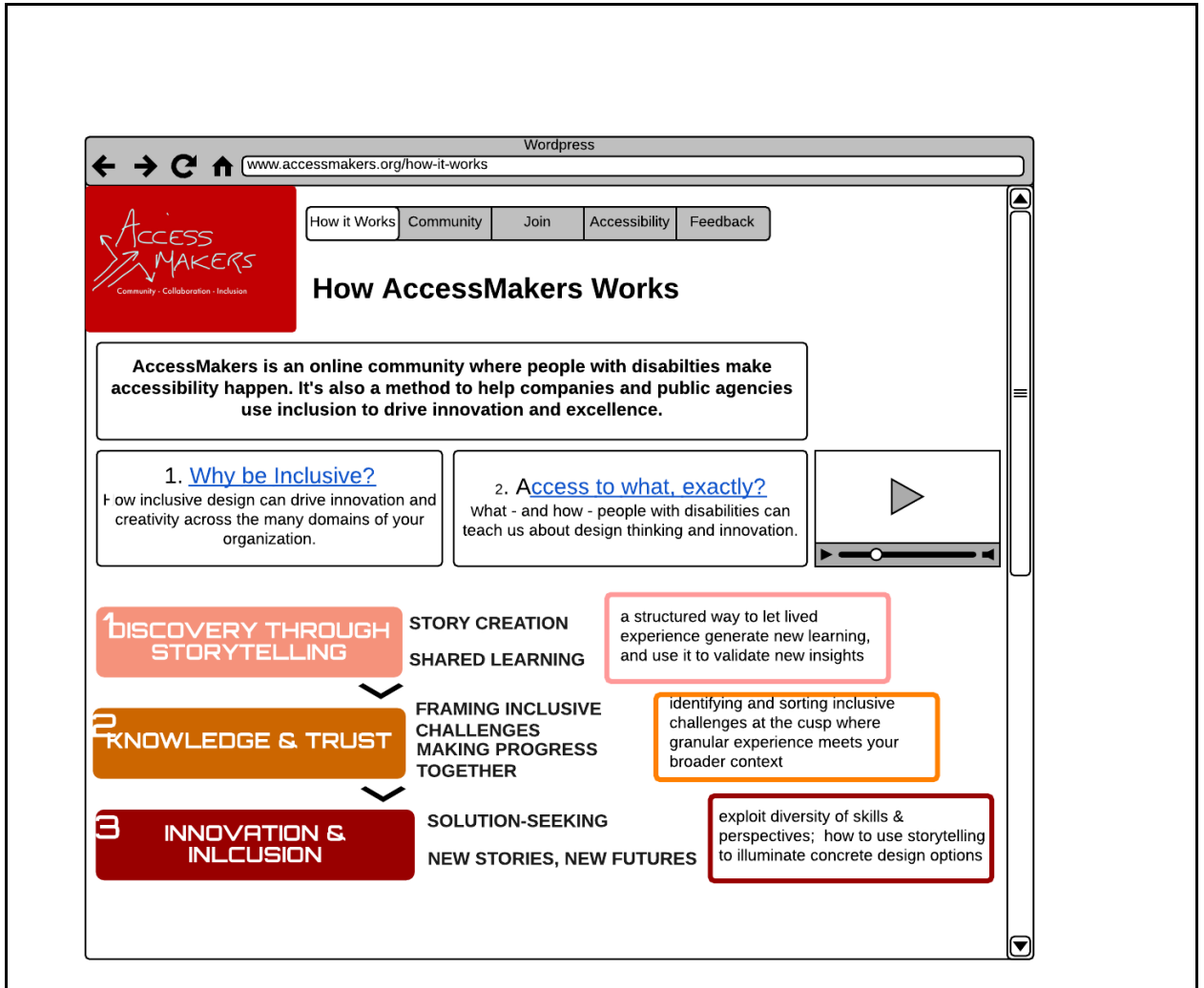
Below you'll see some 'wireframe' web page - these are low-fidelity diagrams of what's possible on the internet.

Please take a look and consider the features described here - would they benefit you? What would you want/need that is not mentioned here? What would be your hopes or concerns about participating in a community like this?

> **How it Works -** explanation of what AccessMakers is, and how to take advantage of it. [NOTE: at this time, this page is for organizations that want to gather stories; a separate 'how it works' will also be created for individuals who want to tell a story]
>
> On this page, the components of the AccessMakers workshops are summarized in the main window. An introductory video (tutorial) is available to the right.

Wordpress

www.accessmakers.org/how-it-works

How it Works | Community | Join | Accessibility | Feedback

How AccessMakers Works

AccessMakers is an online community where people with disabilties make accessibility happen. It's also a method to help companies and public agencies use inclusion to drive innovation and excellence.

1. [Why be Inclusive?](#)
How inclusive design can drive innovation and creativity across the many domains of your organization.

2. A[ccess to what, exactly?](#)
What - and how - people with disabilities can teach us about design thinking and innovation.

1 DISCOVERY THROUGH STORYTELLING

STORY CREATION

SHARED LEARNING

a structured way to let lived experience generate new learning, and use it to validate new insights

2 KNOWLEDGE & TRUST

**FRAMING INCLUSIVE CHALLENGES
MAKING PROGRESS TOGETHER**

identifying and sorting inclusive challenges at the cusp where granular experience meets your broader context

3 INNOVATION & INLCUSION

SOLUTION-SEEKING

NEW STORIES, NEW FUTURES

exploit diversity of skills & perspectives; how to use storytelling to illuminate concrete design options

---

Community - On this page, organizations can create their own portfolio to collect accessibility stories that are relevant to them, and individuals who face access barriers can submit stories to organizations.

In the image below, note the features of this page:
- links below each logo tell visitors they can 'tell a story' that relates to this organization, or 'support' in other ways (offer design or planning advice, or other resources)
- any company, agency or group can join AccessMakers here, and start gathering stories through the portal
- on the right hand side, there is a list of categories of organizations already signed up,

which can be accessed by visitors ('Open Collections') who may want to learn from them about access solutions
- below the Open Collections listing is a Twitter pane, showing current #AccessMakers stories on social media - this is a regular stream of mini-stories that can be followed up by others in the online community via tagging (adding keywords) and formulating the content into fuller stories for action.


Analog: www.amara.org/en/community - Amara's mission is to reduce barriers to communication and promote democratic media around the world. It is a site for crowdsourcing video captioning - in many languages - for the deaf, hard of hearing as well as diverse language groups. Organizations like TED Talks, Scientific American, and the U.S. National

John D. Willis

Archives have teams of volunteers around the world that caption their videos via the Amara website.

Story Portfolio - this is where organizations collect and review stories from their stakeholders, and it also provides an interface with the wider online AccessMakers Community (that is, storytellers who didn't participate in your workshop but who have something to say). Here, your stories are arranged 'bullet point' style with tags (next to the photo of the storyteller) so you can group them in different ways. To the right is your list of categorized tags/stories, and below that a list of tools and methods for working on solutions (the 'Maker Space').

AccessMakers: A Platform for Inclusive Innovation
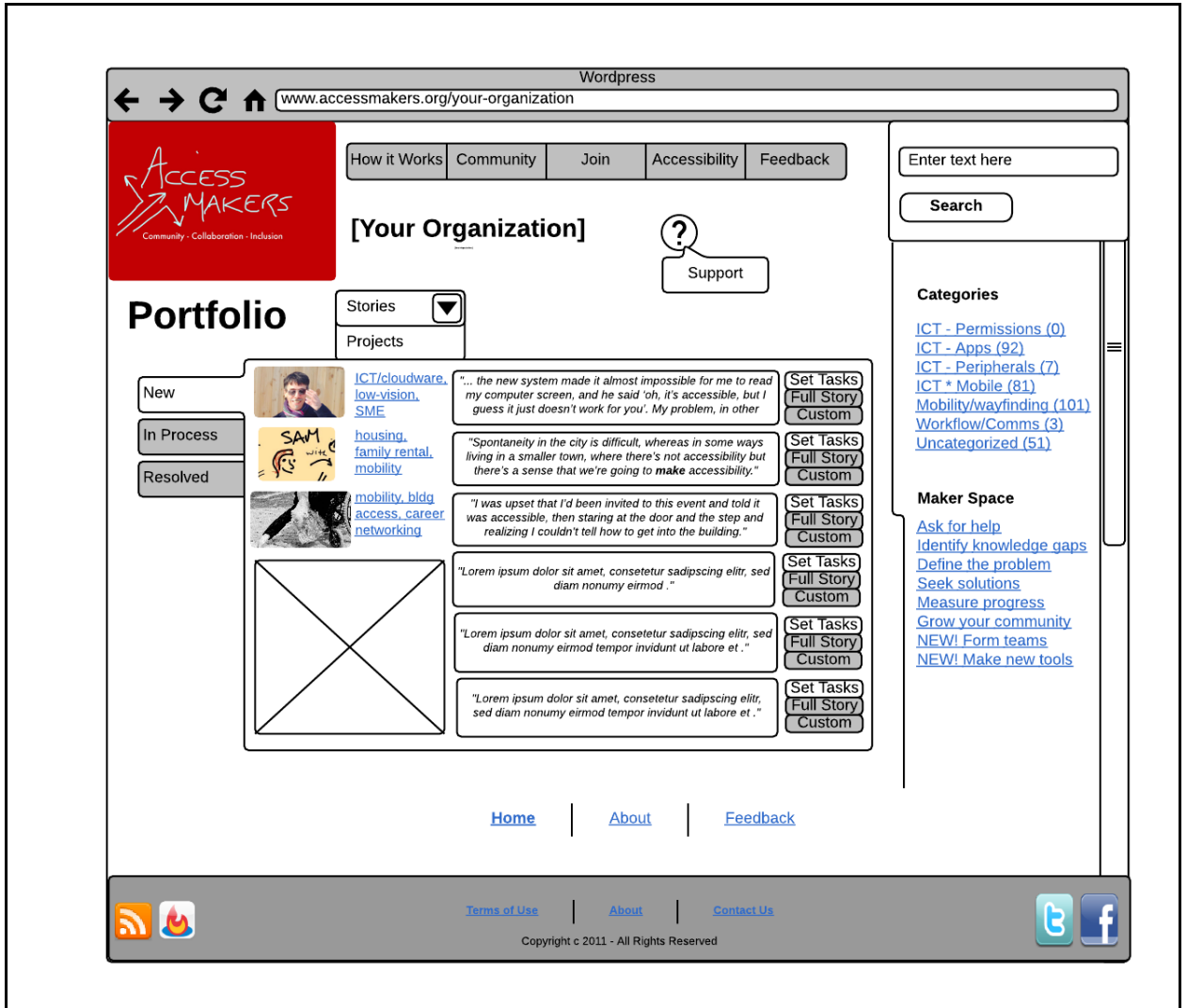
Story Summary - this is a short form of a specific story. This page provides links to stories from the same person, in the same category, and other sorting options. One of the most important features of this page are the tools for 'community tagging' - letting anyone in the AccessMakers community provide additional data to enrich the story - for example, identifying specific organizations; highlighting important design methods or technologies that could be part of the solution; pointing to analogous situations where a solution was found.

[wireframe]

John D. Willis

Projects - an organization can tag and re-organize it's story data into 'projects' that suit their needs - some typical projects might be ->

- 'client-facing ICT' for access issues relating to digital properties that are meant for customers and clients to use
- 'regulatory' - for stories that aid staff in managing compliance with the *Accessibility for Ontarians with Disabilities Act* (AODA).

This page allows for 'project tagging' - that is, the assignment of keywords to stories so that you can sort by task giver, skill sets, reporting structures, or connection to other projects.

[wireframe]

Story Journal - For individuals, this is the primary interface with the AM community, containing:

- Portal to tell a new story, based on the storytelling technique in the AccessMakers workshop, *Discovery Through Storytelling*
- List of my stories
- List of my organizations
- List of my projects