The 1000 Voices Project: Online reflective multimodal narrative as a research methodology for disability research

Abstract

This article outlines the research approach used in the international 1000 Voices Project. The 1000 Voices project is an interdisciplinary research and public awareness project that uses a customised online multimodal storytelling platform to explore the lives of people with disability internationally. Through the project, researchers and partners have encouraged diverse participants to select the modes of storytelling (e.g. images, text, videos and combinations thereof) that suit them best and to self-define what both "disability" and "life story" mean to them. The online reflective component of the approach encourages participants to organically and reflectively develop story events and revisions over time in ways that suit them and their emerging lives. This article provides a detailed summary of the project's theoretical and methodological development alongside suggestions for future development in social work and qualitative research.

Keywords: Reflective multimodal narrative; online research; narrative research; disability; participant-centred.

1000 Voices: Reflective online multimodal narrative inquiry as a research methodology for disability research

The purpose of this article is not to report research "results" or "findings" *per se* but rather to present and reflect upon the value of "reflective multimodal narrative research" more generally in the context of disability and social work. We offer here a summary of our own forays into reflective multimodal research as part of the international 1000 Voices project (www.1000voices.edu.au) and an introduction to our key methodological and theoretical learnings along the way. Much has been said about the need to give marginalised people in our society a "voice". These conversations have emerged across many contexts including participation in planning and policy making processes (see Finney and Rishbeth, 2006; Ginsburg, 1999; Mertens et al., 1994), health and human services practices (see De Souza, 2004; Sokoloff and Dupont, 2005), and post-positivist research practices (see Ashby, 2011; Maton, 2000).

   As we have argued in detail elsewhere (Matthews and Sunderland, 2013), the explosion of interest in digital and other life narratives over the past 30 years has been profoundly shaped by political imperatives and epistemological perspectives. We follow Norman Denzin's argument here that a political commitment to autobiographical

narratives, "to the value of individual lives and their accurate representation in the life story document" (cited in Goodson, 2006: 14), is a response by liberal and left scholars to the legacy of the New Right in America and elsewhere. Facilitators of digital storytelling for example have sought out groups considered to be marginalised, disadvantaged or disempowered in "mainstream" discursive environments, encouraging them to tell their stories in the interests of "having a voice". These facilitators have been committed to allowing the diverse experiences of individuals to be heard, relatively unmediated by expert opinion, interpretation, or analysis (for example Gubrium, 2009; Hull and Katz, 2006; Meadows, 2003). In the words of Aline Gubrium (2009), "The aim is to have participants construct their own digital story and to avoid having the experts, the trainers, construct stories for them" (p. 187).

Making space for the voices of others is particularly important in the area of disability research, given that self-advocates with a disability have fought strenuously to assert their own voices and experiences for decades (see Charlton, 1998; Rowland, 2001; Yeo and Moore, 2003). As researchers engaged in a long term project that aims to amplify the voices of people with disability, we have grappled with the above considerations at the theoretical, methodological, and practical levels.

Through collaboration across the disciplines of social work, applied ethics and human rights and media studies, each represented within the project team, we identified synergy between the need for phenomenological research that documents emplaced and embodied daily experience (see Merleau-Ponty, 1996; Pink, 2009) of disability, and narrative research methods that provide a broad view of individual experience within socio-economic and cultural contexts (Hampton, 2004: 263). Adopting a phenomenological-narrative approach acknowledges that as social beings we experience and make sense of places, things, others, and ourselves via the medium of the body (Davis, 1997; Pink, 2009). Just as human experience is always embodied, it is also always emplaced (Howes, 2005; Pink, 2009): that is, 'bodies are not simply abstractions… but are embedded in the immediacies of everyday, lived experience' (Davis, 1997: 15. See also Merleau-Ponty, 1996: 24, 44).

Phenomenological-narrative approaches are relevant for disability research in social work because narratives and narrative data can mediate between individual embodied experience, discourse and action, events and structures, individuals and society, and memory and political action (see for example Onocko Campos and Furtado, 2008: 3). Following Pink (2011), we argue that, when used sensitively and flexibly, multimedia narrative methods in particular can enable participants to richly communicate in their own

words embodied and emplaced experiences that are relevant and important to them. As acknowledged by many authors, (see for example Bochner and Ellis, 2003; Dennis, 2000; Hamilton and Atkinson, 2009; Hampton, 2004: 263; Manning, 2010), life stories prepared using creative art forms and multimedia (images, text, film, and audio) allow creativity and flexibility for diverse research participants – including people with disability and culturally diverse communities – because participants can choose to communicate using their favoured communication media. Story telling has also proven to be therapeutic for individuals who have experienced disabling illness or trauma (McGrath et al., 2011).

The 1000 Voices project was launched in December 2009 as an international web-based platform for gathering and displaying digital life stories about the lived experience of people with disabilities. At September 2013 the project had 148 registered members and displayed 75 stories on the website, though stories withdrawn from display by their authors are not included in this total. The average age of storytellers participating between December 2009 and January 2013 was 38.4 years with oldest participant aged 77 years and the youngest participant (who participated with parental consent) aged 10 years. While the bulk of stories submitted over this period were in written form (n=88) the website also includes five collections of photographs and three short films. Remaining stories can be considered "multimodal" in that they included multiple modes of communication within the

one story "text". This included for example 22 poems and one "Acknowledgement" in a collection titled "Charlie's Poems" (see http://1000voices.edu.au/charlies-poems), which appears on the website as 23 short films with a written title and a text read aloud by the author.

This paper summarises our experiences and learnings developed through 1000 Voices with the hope that they can usefully inform others who wish to attempt this kind of research. We first share the philosophical, theoretical, and methodological perspectives that underpin the project as a result of our and our participants' and advisors' ongoing grappling with issues surrounding narrative research and voice. We then provide a summary of the project's online data collection methods that have emerged through participant interactions with the 1000 Voices online platform. In presenting the project in this way, we aim to extend and critically reflect upon current understandings of the scope of long term online narrative projects to "give voice" to marginalised people, and extend the potential for this kind of storytelling to effect social change.

Philosophical and theoretical underpinnings

As indicated above, 1000 Voices proceeds from the assumption that all human experience is embodied and emplaced (Merleau-Ponty, 1996; Pink, 2009). Narrative, in this context, is

seen as a form of storytelling, sense making, and research that both arises from and contributes to individual and collective social experience (Onocko et al., 2008; Riessman, 1993). Following others, we acknowledge that multimedia narratives offer a sensorially and contextually rich way of communicating embodied and emplaced experience that offer story "listeners" a chance to learn about and reflect upon *another's life* (Dennis, 2000; Pink, 2011).

Many writers on oral history, life narratives, and digital storytelling have regarded such stories as offering a voice to disadvantaged people whose perspectives have been silenced or marginalized (Burgess, 2006; Gubrium, 2009; Hartley and McWilliam, 2009; Lambert, 2009; Rossiter and Garcia, 2010). In such accounts, life narratives in their various forms are viewed as offering privileged access to people's experiences.

Few within this tradition would maintain a naïve expectation that narratives offer direct access to hidden histories or a simple account of previously unknown realities. Most writers, particularly those discussing life narratives that describe pain, marginalization and trauma, stress that such retellings by their nature involve elisions, rearticulations and reframings - even factual inaccuracies (Bennett, 2003; Felman 1992; Gigliotti, 2002). While information about social life may be sought by researchers in these accounts (see for example Bytheway, 2009; Hamilton and Atkinson, 2009), the grounding concept for

phenomenological-narrative research is *experience* rather than the unmediated real. Life narratives are researched for what they tell us of the narrator's *experience*, not of the narrator's *life*. Further, as Hänninen (2004) and Polkinghorne (2007) argue, researchers and others who use narrative data as evidence for decision making must navigate the complex, dialogic, and dynamic interplays between the "told", "inner" and "lived" modes of participant narrative (Hänninen, 2004: 69). In this respect we are asked to acknowledge that "told" stories are always only *partially* told. Likewise, stories are always subject to the participants' and broader society's ever-shifting experiences, insights, and access to resources for meaning making. The meaning and significance of participant stories change over time both for storytellers and listeners.

As a way of enriching the existing theoretical perspectives on phenomenology, narrative, and multimodality, 1000 Voices draws on the perspectives of life narrative scholars who describe their object in terms of "auto/biography". This perspective on life narrative emphasises the intersubjective and always/already socially organised nature of life stories, within the discursive framing of "experience". The agency and experience that are stressed in other accounts of life narrative are not ignored or downplayed in this perspective, but rather are contextualized and complicated. Liz Stanley marks this emphasis on life experience within its social context as a shift from a stress on "from self-made

women" to "women's made-selves" (Stanley, 2000). Stanley contrasts framings of life story telling which see it primarily as an individual project of self-expression, with her own view that life story telling is inextricably connected to institutions and the government of populations. Stanley argues that the 'audit selves' produced in for example CVs, medical histories or immigration applications are not just a simplification or falsification of people's real experiences and histories but are, at least in part, constitutive of them (Stanley, 1996: 50). Stories 'coaxed', in Smith and Watson's terms (Smith and Watson, 1996), from people by institutions not only frame people's material lives, but are adapted and deployed – if not always entirely or willingly – in the construction of the "interior" selves more often imagined as the terrain of life story telling.

Methodological underpinnings

Narrative research that aims to have transformative social outcomes is perhaps never easy. The "excluded voice thesis" that underpins much narrative research in disability suggests that narrative methods "provide access to the perspectives and experience of oppressed groups who lack the power to make their voices heard through traditional modes of academic discourse" (Booth and Booth, 1996: 55). Narrative researchers have argued that narrative data provides a more holistic and respectful representation of a person's life in

context (e.g. family, social, political, and cultural contexts) than positivist, reductionist research methods such as surveys or structured interviews (Garden, 2010; Reissman, 1993; Sunderland et al., 2009).

As Booth and Booth (1996) have observed, though, the process of "giving voice" and building holistic representations of a person's life through narrative research can be complex when research participants experience diverse communication, intellectual, and physical abilities. For instance, some participants may have limited physical and geographic mobility; or have challenges with "inarticulateness", "unresponsiveness", and problems with time understanding and communicating experience over time (Booth and Booth, 1996: 56-57). All of these factors can affect participants' inclusion in and enjoyment of narrative research processes.

Unfortunately, researchers' response to these challenges to participation has often been to exclude data from people with diverse competencies from the research (see for example Lesseliers et al., 2009). On the other hand, some studies have responded by spending more time on developing relationships with participants over several encounters, and using alternatively structured questions and stimulus material (such as images and video) to elicit narrative (see for example, Atkinson, 2004; Booth and Booth, 1996).

In addition to carefully considering issues surrounding recruitment, researchers and others who use the data generated through storytelling projects should also consider how participants' agency can be maintained during the data analysis and dissemination phases of research. As Polkinghorne (2007) identifies, "[n]arrative research issues claims about the meaning life events hold for people. It makes claims about how people understand situations, others, and themselves" (p.476). While narrative researchers have advanced many methods for heightening ongoing researcher-participant "dialogue" in data creation and analysis (see Hones, 1998), less has been said about how participants can maintain agency in policy settings and other recontextualisations of narrative data (see Matthews and Sunderland, 2013).

Process for collecting and creating life story data

In response to the above considerations, disability researchers and collaborators have sought to devise creative and inclusive methods for collecting and creating disability life story data (see Atkinson, 2004; Booth and Booth, 1996; Hayashi and Rousculp, 2004; Rose, 2008). Written and verbal disability narrative research projects have often included iterative processes of recording participant stories. This may involve interviewing and biographical writing or scribing – and later checking with the participant that the

interviewer's or scribe's interpretations of the story were correct. Participants are often given opportunities to add, change or remove content before the final transcription or representation of their story is released (see for example Hayashi and Rousculp, 2004).

Where the focus of the narrative research is on the past, the above methods have been combined with stimulated recall techniques with participants and documentary history methods such as collecting participants' case files and medical records, institutional historical information, and family histories (see Atkinson, 2004). A relatively small number of disability narrative studies have used methodologies such as "photovoice" narratives and digital stories to connect peoples' lived experience with decision makers (see for example, Jokinen et al., 2009; Kaylor, 2007; Manning, 2010; Tijm et al., 2011). Despite advances toward multimodality in narrative theory and methodology generally (see for example Ashby, 2011; Doloughan, 2011) disability researchers have not yet widely tested the relevance or applicability of "multimodal" and "intertextual" storytelling techniques to match participants' diverse abilities and preferences. In this context, a multimodal text is one in which text and images are combined to serve the narrative purpose. Intertextual storytelling here refers to the shaping of one text's meanings by other texts.

Principles for data creation in 1000 Voices

Extending existing narrative research in offline settings, we sought to develop data creation

and collection methods that are as enabling and "unfettered" as possible for participants.

The principles we have developed for data collection are outlined below.

Using participants' preferred ways of representing

Feminist and critical language theorists have long recognised the ethical and political

significance of forcing people to use a language or way of representing that is not "their

own" or is not one within which they are comfortable and fluent (Bakhtin, 1981; Beetham,

2002; Gilligan, 1982; Haraway, 1999). If a narrator's preferred and most "authentic"

medium of communicating is song or poetry, image, or a written or spoken language other

than that of the researcher, a standard interview-based data collection method may leave

much to be desired in terms of narrative content and expression.

In terms of data quality, a narrator's fluency and talent in a particular mode of

communication will affect what is presented: what themes, continuity structures, and

metaphors are created; how history and the self are presented; how much content is

presented in the formats allowed; in what order; and so on. How a person spells,

punctuates, capitalises, and arranges sentences is also an important and often creative part

of 1000 Voices written narratives which we have striven to leave "as is" (i.e. uncorrected

by journal editorial standards) when publishing material in academic journals. It is both a

politico-ethical and methodological imperative (in the interests of validity and

trustworthiness) to encourage participants to choose and work within the modes of

communication with which they are most familiar and comfortable. As researchers we must

continuously ask: who gets to speak and how? To what extent are we limiting this

interaction to match our own abilities as researchers? Dennis (2000) raises a pertinent

question in this regard: "How can we be sure of authenticity when the very production of

the voice, or gathering of the story, may in itself be a form of oppression?" (p. 24).

Incorporating creative abstract expression and "testimony"

Consonant with previous narrative research with vulnerable participants (see Funkenstein,

1993; Sillato, 2008), we recognise that not all things can or will be described by

participants in any storytelling project. This is not to say that all participants in the 1000

Voices project have been exposed to traumatic experiences, but there may be topics which

are socially or culturally taboo, illegal, censored, private, or painful for any person to share

whether or not they are disabled. Participants may therefore avoid participating, exclude

certain experiences from their stories, or use alternative creative methods to abstractly represent their experiences. One example of this kind of abstract creative representation emerged in Amos Funkenstein's (1993) work with holocaust survivors. Funkenstein describes ways in which survivors of Nazi concentration camps painted and exhibited their experiences to achieve both therapeutic and political outcomes. In her work with survivors of torture during the latest dictatorship in Argentina, Maria del Carmen Sillato (2008) also used creative writing to help torture survivors "talk" about their experiences. Sillato (2008) notes that many of the experiences recorded via the creative writing process were *unspeakable* for their authors prior to the project. Upholding the dignity, and indeed safety, of some of narrators hence requires ongoing processes of critical reflection and collaboration. This has been especially important in 1000 Voices when working alongside narrators with intellectual impairment who have experienced traumatic events. Processes of collaboration here spanned many months and many iterations of what was to be included and what was to be left unsaid.

Valuing what is not said

Silences – or absences in representation of certain topics – both produce and reproduce *shared* meaning (see Sheriff, 2000; Sunderland et al., 2009). Methodologically, this may be problematic because it can be difficult to verify the researcher's interpretations of what absences in a narrative or conversation might mean. One common solution is additional ethnographic inquiry into the contexts and collaborative practices of silence and silencing at work in the given participant community. Another is to allow long periods of reflection and trust building between participants and researchers. Giving participants a high degree of discretion enables them to determine how, when, and why they share their stories, and also to self-identify where "silences" exist through collaborative analysis and dissemination activities. The treatment of silence is still a work in progress for us, as many of the participants communicate their stories in the privacy of their own life situation, and may not desire to engage in more direct contact with the research team.

Steps towards and outcomes of data collection

With these principles front and central, we created 1000 Voices to incorporate different modalities of representation. This provided avenues for people to choose different ways of representation – albeit with some limitations. We also grappled with dilemmas around

having another person assist and support the creation of narratives, weighing up authenticity against exclusion from the project.

By encouraging individual research participants with disability to select the communication mode or combination of modes that best suits them and their intended story, we aim to hand over significant decision-making power and flexibility in the research process to participants. In particular, we want the 1000 Voices approach to as closely as is possible reflect the *natural* ways that humans make meanings: that is, through multimodal communication (Lemke, 1998, 2009). Importantly, we do not view multimodal artefacts in participant stories as simply an "illustration" of a spoken narrative (though in some cases this might be true). Rather we acknowledge that visual, aural, and other modes of communication can function as languages in themselves (Kress and van Leeuwen, 2000).

As indicated, the concepts of multimodality and reflection that have come to underpin the 1000 Voices approach are to some degree present in many narrative studies reported in current academic literature. The primary difference with 1000 Voices is the *degree* to which researchers are able to free up the research data collection process in an online setting, to include modes of communication that are as dynamic, diverse, and participant driven as possible. Our focus on facilitating *reflective* narrative over a relatively unlimited timeframe – which has largely been shaped by how participants themselves use

the project website – also means the 1000 Voices data collection periods are extended and ongoing. This flexibility is not usually possible for fixed term research projects.

The resulting key steps involved in the 1000 Voices approach during our pilot development phase (December 2009 – January 2012) were as follows:

1. Establish a reference group to advise on key aspects of the project;

2. Establish a pilot online public storytelling platform that would cater for multimodal storytelling;

3. Advertise the project nationally and internationally via email networks and conference presentations to disability service providers, policy makers, and academics;

4. Team members invite all interested (self-selecting) participants to submit a story "about their lives" using any communication mode or combination of modes they desire. Participation is voluntary and self-initiated. Anyone who identifies as "living with a disability" is welcome to participate;

5. Participants upload stories using an individual user account after completing an online ethics consent process and demographic survey during which they identify the nature of their disability;

6. Participants choose: whether to upload stories using a nickname or their real name; what topics they would like to represent; how they will represent these topics; and how long they would like to take to prepare their story;

7. Participants are able to add, revise, and remove story elements or their entire story at any time through a secure user account. Research facilitators are on hand to assist with creating stories, uploading, revising, or removing stories.

The stories that have resulted from these steps have been unexpected, diverse, and extremely engaging.

Some participant stories, such as Phil Deschamp's collection titled *My Photos Are Rubbish! Abstract Expressionism By Phil Deschamp* (see: http://1000voices.edu.au/my-photos-are-rubbish-abstract-expressionism-by-phil-deschamp) centre around collections of photos or artworks with added textual descriptions of the images. Unexpectedly, participants have also frequently created what might be called "hyper-modal" (Lemke, 2002) narratives, which include links to existing story artefacts such as online blogs or presentations they have created (see for example Ingrid Hindell's story titled

"INAPPROPRIATE BEHAVIOURS" – NOBODY'S VIRTUE, NOBODY'S VICE? at

http://1000voices.edu.au/inappropriate-behaviours-nobodys-virtue-nobodys-vice).

In some cases participants such as Korey (see

http://1000voices.edu.au/author/Korey) spontaneously returned to the site to update their

stories with messages about new experiences of higher education. Others, such as Jason

Copeland, uploaded extended written stories covering different time periods and events in

their own and others' lives (see: http://1000voices.edu.au/greatest-achievements-how-i-

launched-housing-co-op-1970s).

The resulting reflective multimodal narratives included on the 1000 Voices site

constitute an extraordinarily meaningful 'genre chain' (Fairclough et al., 2002) of

representations that have emerged via predominantly participant-directed processes of

reflection and narrating over time, both within and beyond the project. Examples of the

various artefacts and "movements" of storying that have been included in the project to date

are illustrated in Figure 1.

[INSERT FIGURE 1 APPROXIMATELY HERE]

Within the multimodal narrative movements outlined in Figure 1 we can define sub-narratives, narrative components, and phases of narrative development. While spoken and written narratives have similar features, the 1000 Voices process has allowed us to capture a series of reflective processes that the limited narrative collection of a spoken interview would not have yielded. The diagram explicitly acknowledges that participants' narratives began before the research was even conceived, and links the narratives they have produced for 1000 Voices with other, enriching, narratives they have published elsewhere.

Missing voices

Aware of the way that life storytelling can be profoundly shaped by way people are invited, encouraged or instructed in storytelling, the initial intent of 1000 Voices has been to involve and assert the rights of many people with disability through the use of their own "unfettered" narrative. However, it has been a key learning in this project that some people need significant support to tell their story, either because of their reliance on others around them to communicate, or a sense that their lives were too "ordinary" to warrant participation. To ignore these groups of participants would mean the project would privilege those people with disability who have greater access to technology, more "mainstream" communication styles, and higher confidence levels. The project team's

initial focus on online self-initiated participation had just these consequences. Early

analysis of participants' demographic data and consultation with our advisory group

sharpened our awareness of the voices that were missing from the 1000 Voices database,

drawing our attention to the limits of a focus on the limits of the autonomous narrating self.

After much reflection, we have sought the participation of these "missing voices"

through various means. Firstly, we expanded our definition of narrative to include the use

of intermediaries for those with higher support needs (Walmsley and Johnson, 2003). In

most cases the intermediaries have been those close to the person, such as parents or others

who know and care about the person. Authenticity of voice may have been compromised

by such a process, but the team made the conscious decision that a "filtered" story was

better than no story at all.

Secondly, we have had to address the reality of the digital divide and lack of access

to many resources for many people with disability who largely live in poverty. We

addressed this in a number of ways: providing cameras and video equipment to participants

where possible and facilitating sessions within community agencies where computers could

be accessed. This proved to be challenging in that even many community organisations

have few material resources, poor access to the internet and insufficient staff to offer

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support. Developing a mobile app for the project is underway to increase access in areas where computers and internet access are not available.

Thirdly, as researchers we have engaged in facilitative participatory narrative processes with people less likely to self-initiate sharing stories. Significant time and resources have been spent journeying alongside people with mild intellectual disability who were supported by a non-government disability agency to tell their stories using various media. We have found this to be a very skilled activity, which requires considerable reflexivity on the part of the facilitators, as well as ongoing negotiations and reliance on third parties. Once again, this practice has somewhat moved away from the core principle of 1000 Voices concerning authentic representation, but was considered warranted in the interests of inclusion. Our awareness that all life stories are, in some respects, "coaxed" (Smith and Watson, 2006) – drawn from tellers in particular forms and on particular occasions by particular institutions, trainings and conventions – made this decision an easier one to think through.

Finally, the project has had to recognise a common assumption made by some participants that only stories which are deemed entertaining or spectacular are worthy of sharing. Our challenge has been to demonstrate the "extraordinariness of the ordinary" and therefore to provide encouragement to people to share their everyday lives. In Lorna

Hallahan's words, 1000 Voices aimed to foreground "the disabled everyday" (Hallahan, 2009), as opposed to dramatic, tragic or heroic narratives that are frequently narrated about people with disability. Our intervention in the project has therefore become a necessary "evil", in order to prevent the project becoming another medium in which subdivisions between groups of people with disability are recreated (Walmsley and Johnson, 2003).

Implications of multimodal reflective narrative research for social work, disability, and qualitative research

Development of suitable analysis approaches for large scale multimodal collections of narratives like 1000 Voices project is ongoing (see Matthews and Sunderland, 2013). Preliminary reflections on the project suggest that while much social work research is strongly grounded in qualitative traditions, there is a need for further work around narrative inquiry and the use of online technologies in qualitative research. The project has also produced many dilemmas around research ethics such as consent, confidentiality and the uses of research data. The implications for research and advocacy of large scale life story collections which amass textual and image data are also largely unknown.

Working alongside our narrators has yielded many insights into the nature of appropriate support for people with disability and the relationships between social work

practitioner and the person they support. This has been particularly instructive in work with people with intellectual impairments. The development of a collaborative narrative requires skills in establishing rapport and trust, in determining appropriate ways to offer support while maintaining autonomy, choice and self-determination and is one of the most powerful ways of working in client centred approaches so central to disability practice.

Using the 1000 Voices project for social work education has yielded a number of interesting possibilities for broader use of multimodal life narrative. The collection has been used as a way of introducing beginning students to the multiplicity of lived experiences of people with disability and the complex ways in which identities are formed, understood and interpreted. The stories have potential for engagement with the notions of difference, diversity, stereotypes and prejudice. There are also possibilities for field education and policy practice though these have yet been explored.

Reflecting on our experiences over several years, it is apparent there is still much we do not know about our narrators and how their stories are created and developed. Equally, many of our aspirations and ideals for the project remain unaddressed and unrealised. Our goal of "unfettered" narratives has limitations. We acknowledge that while we have handed as much control as possible over to participants in the online setting, we do not have a full picture of others (e.g. family members, carers, or spouses) who may have

been involved in various stages of the process. Further, as discussed in this article, narratives will always be shaped by the limitations of the media through which they are gathered and disseminated and by the meaning making resources on offer to participants as they prepare their own story. In absolute terms, the fully "unfettered" narrative may never be possible. Nevertheless, we argue that our *best attempts* to promote the freedom of voice that so many researchers and activists have called for should be at the top of our minds in all research, particularly that involving potentially vulnerable and previously silenced populations.

Our more recent work with people with intellectual and cognitive impairments has been instructive on many levels. Travelling alongside these narrators in the reflective story creation process has enabled a heightened understanding of the processes of narrative and life story building for these particular people in this particular contexts. We wonder what processes unfold for our other narrators, and how these processes might be different or similar. The unfolding processes of creating a purposive facilitated story has also brought to a more public forum some extremely rare glimpses of the lived experience of hitherto unheard or unseen groups of people with disability (see for example Aaron's story at http://1000voices.edu.au/my-story-3). These "missing voices", which are presented in multimodal format, now have increased visibility within the spectrum of life story

collections. However, such increases in visibility increase are modest with, at best, still emerging potential. Stories on the site are being used in learning and teaching to bring lived experience more directly to the wider student group. International bodies are seeking out the project as a way to bring to the public arena such lived experiences. However, the move from increased visibility to bringing about social change requires further conceptualisation and action. As researcher/advocates the 1000 Voices journey continues.

Conclusion

This article has summarised the key theoretical and methodological underpinnings of the 1000 Voices project and outlined our learnings over several years of grappling, alongside our participants, with the domains of theory, method, ethics and translation intensely within one project. We have proposed directions for future development of online reflective multimodal narrative research in disability and social work. Importantly, 1000 Voices has extended our understandings of narrative research by exploring the possibilities of participant-directed narrative on online settings over time. Participants' capacity to reflect, change and develop stories over time adds an significant dimension to iterative processes fundamental to qualitative research. Further exploration of implications of the iterative affordances of online storytelling is one significant direction for further research.

References

Ashby CE (2011) Whose "voice" is it anyway?: Giving voice and qualitative research involving individuals that type to communicate. *Disability Studies Quarterly* 31(4). Available from http://dsq-sds.org/article/view/1723/1771

Atkinson D (2004) Research and empowerment: Involving people with learning difficulties in oral and life history research. *Disability & Society* 19(7): 691-702.

Bakhtin MM (1981) Discourse in the novel. In: Holquist M (ed) *The Dialogic Imagination: Four Essays* (Holquist MH and Emerson C, Trans.). Austin, Texas: University of Texas Press, pp.269-434.

Beetham M (2002) Speaking together: Heteroglossia, translation and the (im)possibility of the just society. *Women's Studies International Forum* 25(2): 175-184.

Bennett J (2003) The aesthetics of sense memory: Theorising trauma through the visual arts. In: Hodgkin K and Radstone S (eds) *Regimes of Memory*. London: Routledge, pp.27-39.

Bochner AP and Ellis C (2003) An introduction to the arts and narrative research: Art as inquiry. *Qualitative Inquiry* 9(4): 506-514.

Booth, T and Booth W (1996) Sounds of silence: narrative research with inarticulate subjects. *Disability & Society* 11(1): 55-70.

Burgess J (2006) Hearing ordinary voices: Cultural studies, vernacular creativity and digital storytelling. *Continuum: Journal of Media & Cultural Studies* 20(2): 201–214.

Bytheway B (2009) Writing about age, birthdays and the passage of time. *Ageing & Society* 29(6): 883-901.

Charlton JI (1998) *Nothing About Us Without Us: Disability Oppression and Empowerment*. Berkeley and Los Angeles, California: University of California Press.

Cochran PA, Marshall CA, Garcia-Downing C, Kendall E, Cook D, McCubbin L and Gover R (2008) Indigenous ways of knowing: Implications for participatory research and community. *American Journal of Public Health*, 98(1), 22-27.

Davis K (1997) Embodying theory: Beyond modernist and postmodernist readings of the body. In: K Davis (Ed), Embodied practices: Feminist perspectives on the body. Sage, London, UK, pp. 2-26.

De Souza R (2004) Motherhood, migration and methodology: Giving voice to the 'other'. *The Qualitative Report* 9(3): 463-482.

Dennis R (2000) *Nonverbal Narratives: Practitioner Perspectives on Narratives for People with Severe Intellectual Disability* (Unpublished doctoral dissertation). The University of Queensland, Brisbane, Queensland.

Doloughan F (2011) *Contemporary Narrative: Textual production, multimodality and multiliteracies*. London and New York: Continuum.

Fairclough N, Jessop B and Sayer A (2002) Critical realism and semiosis. *Journal of Critical Realism* 5(1): 2-10.

Felman S (1992) *Testimony: Crises of Witnessing in Literature, Psychoanalysis and History*. London: Routledge.

Finney N and Rishbeth C (2006) Engaging with marginalised groups in public open space research: The potential of collaboration and combined methods. *Planning Theory & Practice* 7(1): 27-46.

Funkenstein A (1993) The incomprehensible catastrophe: Memory and narrative. In: Josselson R and Lieblich A (eds) *The Narrative Study of Lives.* Newbury Park, CA: Sage, pp.21-29.

Gigliotti, S (2002). Foregoing Conclusions: Rewriting Visions of the Self and Society in Modernity. *The European Legacy* 7(1): 93-95.

Gilligan C (1982) *In a Different Voice: Psychological Theory and Women's Development*. Harvard: Harvard University Press.

Ginsburg N (1999) Putting the social into urban regeneration policy. *Local Economy* 14(1): 55-71.

Goodson I (2006) The rise of life narrative. *Teacher Education Quarterly* 33(4): 7-17.

Gubrium A (2009) Digital storytelling: An emergent method for health promotion research and practice. *Health Promotion Practice* 10(2): 186-191.

Hallahan L (2009) *Public Testimony: Empowerment or Humiliation?* Proceedings from *The Story of the Story: Life Writing, Ethics and Therapy Conference*. Adelaide, South Australia: Flinders University. 28-30 September 2009.

Hamilton C and Atkinson D (2009) A story to tell: Learning from the life-stories of older people with intellectual disabilities in Ireland. *British Journal of Learning Disabilities* 37(4): 316-22.

Hampton G (2004) Enhancing public participation through narrative analysis. *Policy Sciences* 37(3/4): 261-276.

Hänninen V (2004) A model of narrative circulation. *Narrative Inquiry* 14(1): 69-85.

Haraway D (1999) Situated knowledges: The science question in feminism and the privilege of partial perspective. In Elliot A (ed) *The Blackwell Reader in Contemporary Social Theory*. Wiley, pp.287-301.

Hartley J and McWilliam K (eds) (2009) *Story Circle: Digital Storytelling around the World.* Malden, Mass: Wiley-Blackwell.

Hayashi R and Rousculp T (2004) The "Our Homes, Not Nursing Homes" project. *Journal of Social Work in Disability & Rehabilitation* 3(2): 57-70.

Hones DF (1998) Known in part: The transformational power of narrative inquiry. *Qualitative Inquiry* 4(2): 225-248.

Howes, D (2005) Architecture of the Senses. In: M Zardini (Ed.), *Sense of the City: An Alternate Approach to Urbanism*. Montreal and Baden: Canadian Centre for Architecture and Lars Müller Publishers.

Hull, GA and Katz, ML (2006) Crafting an agentive self: Case studies of digital storytelling. *Research in the Teaching of English*: 43-81.

Jokinen NS, Kelley ML and Martin L (2009) Adults aging with an intellectual disability use "Photovoice" to depict an age-friendly community. *Journal of Policy and Practice in Intellectual Disabilities* 6(2): 119.

Kaylor M (2007) Digital storytelling for students with learning disabilities. In: Carlsen R et al. (eds) *Proceedings of Society for Information Technology & Teacher Education International Conference 2007*. Chesapeake, VA: AACE, pp.621-623.

Kress G and van Leeuwen T (2000) *Multimodal Discourse*. London: Arnold.

Lambert J (2009) The field of community arts. In: Hartley J and McWilliam K (eds) *Story Circle: Digital Storytelling around the World*. Oxford, UK: Wiley.

Lemke J (1998) Multiplying meaning: Visual and verbal semiotics in scientific text. In: Martin JR and Veel R (eds) *Reading Science: Critical and Functional Perspectives on Discourses of Science*. London: Routledge.

Lemke J (2009) Multimodality, identity, and time. In: Jewitt C (ed) *The Routledge Handbook of Multimodal Analysis*. Routledge Chapman & Hall, pp.140-150.

Lemke JL (2002) Travels in hypermodality. *Visual Communication* 1(3): 299-325.

Lesseliers, J Van Hove, G and Vandevelde, S (2009) Regranting identity to the outgraced–narratives of persons with learning disabilities: Methodological considerations. *Disability & Society* 24(4): 411-423.

Manning C (2010) "My memory's back!" Inclusive learning disability research using ethics, oral history and digital storytelling. *British Journal of Learning Disabilities* 38(3): 160-167.

Maton K (2000) Languages of legitimation: The structuring significance for intellectual fields of strategic knowledge claims. *British Journal of Sociology of Education* 21(2): 147-167.

Matthews, N and Sunderland, N (2013) Digital life-story narratives as data for policy makers and practitioners: Thinking through methodologies for large-scale

multimedia qualitative datasets. *Journal of Broadcasting & Electronic Media* 57(1): 97-114.

McGrath P, Holewa H and Skarparis M (Producers) (2011) *Keeping on – Sharing the Journey* [DVD]. Brisbane, Australia: Patient Stories, International Program of Psycho-social Health Research (LFQ) and Leukaemia Foundation of Queensland.

Meadows D (2003). Digital storytelling: Research-based practice in new media. *Visual Communication* (2): 189–93.

Merleau-Ponty M (1996) *Phenomenology of perception*. Motilal Banarsidass Publishe.

Mertens DM, Farley J, Madison AM and Singleton P (1994) Diverse voices in evaluation practice: Feminists, minorities, and persons with disabilities. *American Journal of Evaluation* 15(2): 123-129.

Onocko Campos RT and Furtado JP (2008) Narratives: Use in qualitative health-related research. *Revista de Saúde Pública* 42(6): 1090-1096.

Pink S (2011) Multimodality, multisensoriality and ethnographic knowing: Social semiotics and the phenomenology of perception. *Qualitative Research* 11, 261. doi: 10.1177/1468794111399835.

Pink S (2009) *Doing sensory ethnography*. London: Sage.

Polkinghorne DE (2007) Validity issues in narrative research. *Qualitative Inquiry* 13(4): 471-486.

Razack S (1993) Storytelling for social change. *Gender and Education* 5(1): 55-70.

Research in the Teaching of English, 41(1): 43–81.

Riessman CK (1993) *Narrative Analysis: Qualitative Research Methods* (Series 30). Newbury Park, CA: Sage.

Rose I (2008) Autistic autobiography or autistic life narrative? *Journal of Literary Disability* 2(1): 44-54.

Rossiter M and Garcia PA (2010) Digital storytelling: A new player on the narrative field. In: Rossiter M and Clark MC (eds) *Narrative Perspectives in Adult Education*. New Directions for Adult and Continuing Education, No. 126. San Francisco: Jossey-Bass, pp.37-48.

Rowland W (2001) Nothing About Us Without Us: Some Historical Reflections on Disability Movement in South Africa. *Disability World Issue* (11) November-December. Available at: http://mail.disabilityworld.org/11-12_01/il/southafrica.shtml

Sheriff RE (2000) Exposing silence as cultural censorship: A Brazilian case. *American Anthropologist* 102: 114–32.

Sillato MC (2008) *Huellas: Memorias de Resistencia* (Argentina 1974-1983). San Luis, Argentina: Nueva Editorial Universitaria.

Smith S and Watson J (1996) Introduction. In: Smith S and Watson J (eds) *Getting a Life: Everyday Uses of Autobiography*. London: University of Minneapolis Press.

Sokoloff NJ and Dupont I (2005) Domestic violence at the intersections of race, class, and gender challenges and contributions to understanding violence against marginalized women in diverse communities. *Violence Against Women* 11(1): 38-64.

Stanley L (2000) From 'self-made women' to 'women's made-selves'? Audit selves, simulation and surveillance in the rise of public woman. In Cosslett T, Lury C and Summerfield P (eds) *Feminism and Autobiography: Texts, Theories, Methods*. London: Routledge, pp.40-60.

Sunderland, N Catalano, T and Kendall, E (2009) Missing discourses: concepts of joy and happiness in disability. *Disability & Society* 24(6): 703-714.

Tijm M, Cornielje H and Edusei AK (2011) 'Welcome to my life!' Photovoice: Needs assessment of, and by, persons with physical disabilities in the Kumasi Metropolis, Ghana. *Disability, CBR & Inclusive Development* 22(1): 55-72.

Walmsley J and Johnson K (2003) *Inclusive Research with People with Learning Disabilities*. London: Jessica Kingsley Publishers.

Yeo R and Moore K (2003) Including disabled people in poverty reduction work: "Nothing about us, without us". *World Development* 31(3): 571-590.