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## **Title**

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

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## **Abstract**

This article outlines the research approach used in the international 1000 Voices disability life stories 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 disabilities internationally. Through the 1000 Voices project, researchers and partners have encouraged diverse participants to select the modes of storytelling (e.g. images, text, videos) that suit them best and to self-define what both “disability” and “life story” mean to them. The 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 life stories. In this article, team members reflect on how the project extends on previous narrative research in disability, and outline the key theoretical and methodological developments that have emerged over the first four years of the project.

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

## INTRODUCTION

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, 2006; Ginsburg, 1999; Mertens et al., 1994), health and human services practices (see De Souza, 2004; Sokoloff & Dupont, 2005), and post-positivist research (see Ashby, 2011; Maton, 2000). However, any thoughtful conversation that deals with the notion of “giving voice” will inevitably encounter a range of challenging social, political, and methodological quandaries. This is not least because the very notion of “giving” another person “a voice” assumes that: a) someone is systemically silenced through entrenched inequitable and undemocratic socio-political practices; b) someone else is offering what they assume to be politically salient processes that can cut through entrenched processes of silencing to unveil and “liberate” previously silenced voices and experiences; c) there are “marginalised people” who are ready and willing to share their “voices”; and d) there are people – particularly those in positions of social influence and authority – who are waiting to listen to and act upon the voices and experiences that people are in many cases bravely willing to share.

As researchers engaged in a long term project that aims to amplify the voices, experiences, and stories of people with disabilities, we have grappled over time with the above assumptions at the theoretical, methodological, and socio-political levels. Our current work on the international 1000 Voices disability life stories project ([www.1000voices.edu.au](http://www.1000voices.edu.au)) has in many ways been fundamentally motivated by attempting to respond to the above quandaries dialogically across the domains of research ethics, theory, methodology, and translation. The need to respond sensitively and actively to the processes of “giving voice” to others through research is particularly evident 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 Yeo et al., 2003; Rowland, 2001; Charlton, 1998).

Through the 1000 Voices project, we have found great potential synergy between the need for phenomenological research that documents lived experience of disability in oppressive social environments, and narrative research methods which provide a broad view of individual experience within socio-economic and cultural contexts (Hampton, 2005, p. 263). We observe that narrative approaches are particularly relevant for *inclusive* and politically relevant disability research because narratives and narrative data can mediate between discourse and action, events and structures, individuals and society, and memory and political action (Onocko et al., 2008, p.3). When used sensitively and flexibly, narratives can also enable participants to more naturally communicate in their own words aspects of their lives that are relevant and important to them. Life stories prepared using creative art forms and multimedia (images, text, film, and audio) are particularly suited to research with diverse participants – including people with disabilities, and culturally diverse communities – because they are flexible, creative, and can adapt to participants’ communication strengths (Hampton, 2005, 263; Manning, 2010; Hamilton & Atkinson, 2009; Bochner & Ellis, 2003). Narrative story telling has also proven to be therapeutic for individuals who have experienced disabling illness or trauma (McGrath, Holewa, and Skarparis, 2011).

Narrative research that aims to have social outcomes is 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, p. 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 (Reissman, 1993; Garden, 2010; Ellem et al., 2008).

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 use non-standard spoken, written, or expressive communication skills; have limited stimulus recognition (Brown, 2009); 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, 2006, 56-57). All these factors can affect participants' inclusion in and enjoyment of narrative research processes.

Unfortunately, researchers' predominant response to these challenges to participation has often been to exclude people with diverse competencies from the research (see, for example, Brown, 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, 2006).

As we have discussed elsewhere (see Matthews and Sunderland, in press; Matthews, Sunderland, and Chenoweth, in press), 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, 476) 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'. 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 applications of narrative data (see Matthews, Sunderland, and Chenoweth, in press).

This paper summarises our attempts to respond to the above quandaries and trends in disability and narrative research theoretically and methodologically through the 1000 Voices project. To do this we first share the philosophical, theoretical, and methodological perspectives that underpin the project as a result of our and our participants' ongoing grappling with issues surrounding narrative research and voice. We then provide a step-by-step summary of the project's online data collection methods that have emerged through participant interactions with the 1000 Voices online platform. In presenting the 1000 Voices project in this way, we hope to extend current understandings of the scope and potential 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, THEORETICAL, AND METHODOLOGICAL UNDERPINNINGS OF 1000 VOICES**

Writers from different disciplinary traditions and theoretical perspectives have viewed life story narratives in quite disparate ways, highlighting different dimensions.

Many writers on oral history, life narratives, and particularly digital storytelling, have regarded such stories as offering a voice to disadvantaged people whose perspectives have been silenced or marginalized (Rossiter and Garcia, 2010; Lambert, 2009; Hartley and McWilliam, 2009; Burgess, 2006; Gubrium, 2009). In such accounts, life narratives in all their various forms are viewed as offering privileged access to the experiences of these groups of people. 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 (Gigliotti, 2002; Bennett, 2003; Felman 1992).

While information about social life may be sought by researchers in these accounts (e.g. Hamilton and Atkinson, 2009; Bytheway, 2009), the grounding concept for such 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*. 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, p. 69). In this respect we are asked to acknowledge that "told" stories are always only *partially* told. Likewise, the inherent reflective nature of narrative ensures that told 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. This reality has implications both for how we collect and create narrative data, and how we can involve participants in long term inclusive data analysis and dissemination activities.

As we have argued in more detail elsewhere (Matthews and Sunderland, in press), the explosion of interest in life narratives over the past 30 years has been profoundly shaped by political imperatives and epistemological perspectives. We follow Norman Denzin's argument that a political commitment to autobiographical narratives, 'to the value of individual lives and their accurate representation in the life story document', is a response by liberal and left scholars to the

legacy of the New Right in America and elsewhere (cited in Goodson, 2006, 14). Facilitators of digital storytelling 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”. In the main, these facilitators have been committed to allowing the diverse experiences of individuals to be heard, relatively unmediated by expert opinion, interpretation or analysis. 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’ (187).

This political commitment to liberatory speech by marginalized people, with its accompanying epistemological valuing of the category of “experience”, has profoundly shaped the ways in which such multimedia life stories are used. Stories have been collected and archived by cultural institutions like museums and libraries, and “broadcast” online (e.g. Burgess, 2006; Thumim, 2009; Burgess, 2010), but have rarely been systematically and analytically mined for research or policy making purposes. It appears that the political and epistemological assumptions underpinning many life narrative projects can work to hinder the very empowerment they seek to promote (Rich and Chalfen, 1998). Theoretical perspectives that draw primarily from phenomenology, for example, concentrate on eliciting rich descriptions of individual experience, and actively resist discussion of the conditions under which these experiences emerge. Without such discussion, it is not possible to draw out commonalities and themes from a body of stories that might provide evidence of need for change in, for example, policy, education, service provision, clinical practice, or media coverage, relating to a particular group. Rossiter and Garcia (2010) have called participant-produced digital stories “a rich and relatively unexplored source of qualitative data” (49).



Consequently, although we share the political commitments of these liberatory understandings of life narrative, and the utopian hopes for empowerment, self-validation and community formation that accompany both life narrative projects and much writing about them, we have found ourselves obliged to look elsewhere for theoretical foundations that allow us to develop a methodology for our ends. Fidelity to the category of “experience” is clearly critical to the enterprise of offering a rich analysis of multimedia life narratives. However, for the reasons outlined above, collecting descriptions of “experience” is not enough.

As a way of enriching the theoretical perspectives we might offer on multimodal life narratives, and a complement to this emphasis on experience, the 1000 Voices project draws on the perspectives of life narrative writers 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. The leaflet of the Auto/biography Study Group formed under the auspices of the British Sociological Association describes its approach in this way:

an epistemologically oriented concern with the political ramifications of the shifting boundaries between self and other, past and present, writing and reading, fact and fiction... Auto/biography engages analytically with these epistemological problematics and displaces the referential and foundational claims of writers and researchers by focusing on the writing/speaking lives and the complexities of reading/hearing them (cited in Stanley, 1996, 41; see also Cosslett, Lury and Summerfield, 2000)

Stanley, articulating this perspective in the light of feminist accounts of auto/biography, marks the shift in emphasis through her article – “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. She elaborates some examples of such “institutional” life narratives:

the academic CV, employment evaluations and occupational reviews within educational institutions, the production of student records and educational histories; the taking and recording of medical histories; the completion of tax returns, social security claims, immigration applications; the certification of births, deaths, marriages (Stanley, 1996, 50).

Stanley argues that the ‘audit selves’ produced in these kinds of life narratives are not just a simplification or falsification of people’s real experiences and histories but are, at least in part, constitutive of them. 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.

The auto/biographical approach mapped out by Stanley clearly shares assumptions with both critical discourse analysis and, more broadly, interpretivist and post-structuralist approaches within the humanities and social sciences. Each of these traditions refuses to view the stuff of qualitative research – interviews, observations, life narratives – as simply windows onto an already constituted world. Rather, each of these traditions seeks to explore the conditions that allow certain things to be said and make it difficult to say others, and detect patterns in *what* is

said and *how* it is said. This emphasis on the conditions of production of qualitative research sources does not undermine the truth value of these sources but rather raises questions about how, in particular places at particular times, such truths can be told in particular ways, while other experiences may remain silent. From such perspectives, interpretation is always required when making sense of life stories. Thus an account of the historical, cultural and discursive contexts in which life stories emerge becomes a key part of a rich analytical perspective on multimedia digital stories.

Importantly for our purposes, an auto/biographical perspectives focuses attention not only on the conditions under which particular life stories come to be told but also on the challenges of listening to and making sense of such stories. As O'Donnell, Lloyd and Dreher have argued, much less attention has been given in social and cultural theory to listening than to speaking (O'Donnell, Lloyd and Dreher, 2009). The emphasis in many multimedia digital storytelling projects on soliciting, archiving and broadcasting narratives suggests not only that these stories offer access to relatively unmediated "experience", but also that they make sense without further explication or translation. Anna Poletti in her recent unpacking of the generic conventions underpinning much digital storytelling argues that such assumptions are grounded in the notion that digital stories speak to shared human experiences of, for example, "life, loss, belonging, hope for the future, friendship and love" (Burgess, cited in Poletti, 2011, 81). It has been argued, however, that these common themes and ways of speaking are produced, in part, through the training and framing of digital storytelling projects (see also Poletti, 2011; Matthews, 2007). Rather than assuming a bedrock of shared human experiences as a "natural" way to make sense of multimedia life narratives, auto/biographical perspectives suggest culturally and historically specific frames are always used to make sense of such stories. Excavating the nature of such interpretative strategies – as Poletti does in her discussion of Lauren Berlant's concept of the

intimate public as a contemporary cultural technology – makes explicit such schemes and allows their assumptions and limitations to be accounted for. Within critical disability studies, writers such as Anne Finger, Lorna Hallahan and Thomas Couser (Finger, 2004; Hallahan, 2009; Couser, 2004, 2009) have emphasised the importance of unpacking discourses and contexts for storytelling about the lives of people with disability.

While some theorists condemn what they see as the unwarranted intervention of “expert” interpretative frames in the dissemination of life story narratives, auto/biography takes a consciously interpretivist perspective. Auto/biography emphasises the conditions of emergence of particular life stories, detecting patterns that in what is said and unsaid, and focussing on the modes through which it is said. By drawing on such an approach, 1000 Voices does not devalue “experience”. We stand by the political motives that drive our attempt to develop a fruitful methodology for bringing marginalized stories into the centre of policy considerations. We share these utopian investments with auto/biography, which emerges from feminism and emphasises the importance of women’s histories, stories and experiences, but nevertheless draws on post-structuralist and interpretivist frames to understand the meaning of these stories in the contexts of their production.

#### **PROCESSES FOR COLLECTING AND CREATING LIFE STORY DATA IN THE 1000 VOICES PROJECT**

In response to the above considerations, disability researchers and participants have for some time sought to devise creative and inclusive methods for collecting and creating disability life story data (see Booth and Booth, 1996; Atkinson, 2004; Rose, 2008; Hayashi and Rousculp, 2004). 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 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 people’s lived experience with decision makers (see for example, Jokinen et al., 2009; Tijm et al., 2011; Kaylor, 2007; Manning, 2010). Despite advances toward multimodality in narrative theory and methodology generally (see for example Doloughan, 2011; Ashby, 2011; Ryan, 2004) 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 refers to the shaping of one texts’ meanings by other texts.

In the 1000 Voices project we have sought to develop data creation and collection methods that are as enabling and “unfettered” as possible for participants with disabilities in the interests of promoting each participant’s voice. The principles and steps 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; Haraway, 1999; Gilligan, 1982). If a narrator’s preferred “language” is song or poetry, image, or a written or spoken language other than that of the researcher, a standard interview-based data collection method in English language may leave a lot to be desired in terms of narrative content and expression. Further, 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. Hence it becomes 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. This is particularly so when working with underrepresented and marginalised participants (Razack, 1993; Dennis, 2000). 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?’

### **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. 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. While it was illegal for survivors to talk publicly about their experiences in a way that challenged the dominant Nazi representation of the concentration camps, these artists used images to “talk to” public audiences about their experiences, using their art as language. 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’s (2008) work served a dual purpose of providing therapeutic release for the survivors and recording previously unheard testimony regarding the events that took place during the dictatorship. Sillato (2008), who is a survivor herself, notes that many of the experiences recorded via the creative writing process were *unspeakable* for their authors prior to the project. As Sillato (2008) explores, there is an obligation for researchers to uphold the dignity, wellbeing, and even safety of storytellers. In situations where life stories include sensitive material, the "whole story" may never emerge and that must be the participant’s choice.

### **Valuing what is not said [silence]**

In 1000 Voices we assume that the fact that people find it hard to discuss certain topics is extraordinarily meaningful. Silences – or absences in representation of certain topics – both produce and reproduce *shared* meaning (see Sunderland, Catalano, and Kendall, 2009; Sheriff, 2000). Methodologically, this may be problematic because it can be difficult to verify the researcher's interpretations of what silences or 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 in 1000 Voices 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 and outcomes of data collection**

By encouraging individual research participants with disabilities 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 reflect the *natural* ways that humans make meanings: that is, through multimodal intertextual 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 & van Leeuwen, 2000).

As indicated, the concepts of multimodality, intertextuality, 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 1000 Voices 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 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 an online public storytelling platform (pilot version) 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 powerpoints they have created (see for example Ingrid Hindell's story on "Where I May Not Be If I Had Had Cybersex OR – YOU CAN" <http://1000voices.edu.au/where-i-may-not-be-if-i-had-had-cybersex-or-you-can>).

In some cases participants like "Korey" spontaneously returned to the site to update their stories, based on current developments in their lives:

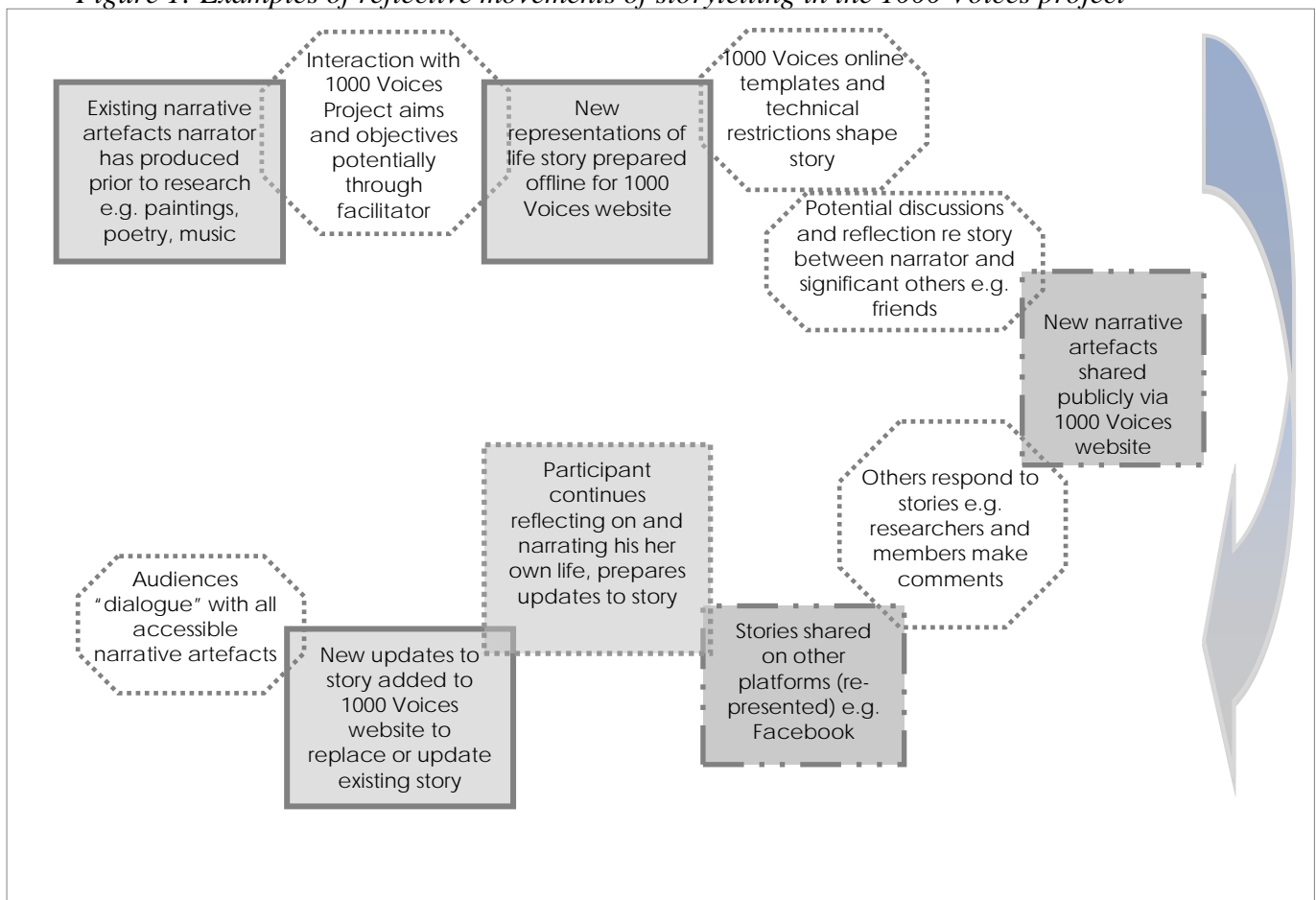
Hi,

i have progressed with my academic education and i am now enrolled to study a Masters of Urban and Regional Planning through Curtin University by distance education. I hope to continue to do a PhD or pursue a future career in urban & regional planning (Korey, 1000 Voices storyteller, June 2010, see <http://1000voices.edu.au/author/Korey>)

Others such as Jason Copeland uploaded multiple extended written stories covering different time periods and events in their lives (see <http://1000voices.edu.au/author/JasonCopeland>).

The resulting reflective multimodal narratives included on the 1000 Voices site constitute an extraordinarily meaningful ‘genre chain’ (Fairclough, Jessop & Sayer, 2002) of representations that have emerged via predominantly participant-directed processes of reflection and narrating over time, both within and beyond the 1000 Voices project. Examples of the various artefacts and “movements” of storytelling that have been included in 1000 Voices to date are illustrated in Figure 1.

*Figure 1: Examples of reflective movements of storytelling in the 1000 Voices project*



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 chronological 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**

The intent of 1000 Voices has been to involve and assert the rights of many people with disabilities 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 (Chenoweth et al., in press). To ignore these groups of participants would mean the project would privilege those people with disabilities who have greater more able people with disabilities in terms of access to technology, more “mainstream” communication styles, and higher confidence levels. At first, the research team inadvertently fell into this trap, and excluded some people by assuming the capacity of all participants to tell their story through the multiple media available.

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 & 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, 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 or borderline 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.

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. Our intervention in the project has therefore become a necessary “evil”, in order to prevent 1000 Voices becoming another medium in which subdivisions between groups of people with disabilities are recreated (Walmsley & Johnson, 2003).

## **Conclusion**

1000 Voices has extended our understandings of disability 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 interesting dimension to iterative processes fundamental to qualitative research. The insights we have gained through grappling

with the domains of theory, method, ethics and translation so intensely within one project, alongside our participants, have value for qualitative research in general, and warrant further research attention.

Reflecting on our experiences with 1000 Voices 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 that 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 via which they are gathered and disseminated and by the meaning making resources on offer to participants as they prepare their own story. Hence, in absolute terms, the fully “unfettered” narrative may never be applicable or indeed achievable for any participant. 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 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 heightened our understandings of the processes of narrative and life story building for some people in some contexts. We wonder what processes unfold for our other narrators, and how these 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 disabilities (see for example

“Charlie’s Poems” <http://1000voices.edu.au/charlies-poems>). These “missing voices”, which are presented in multimodal format, now have increased visibility within the spectrum of life story collections.

The 1000 voices journey continues.

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