KRISTÍN BJÖRNSDÓTTIR
SCHOOL OF EDUCATION, UNIVERSITY OF ICELAND
DAN GOODLEY
SCHOOL OF EDUCATION, THE UNIVERSITY OF SHEFFIELD
HANNA BJÖRG SIGURJÓNSDÓTTIR
SCHOOL OF SOCIAL SCIENCES, THE UNIVERSITY OF ICELAND

Behind the quest for tales, stories and lives: Reflections on narrative research with people with intellectual disabilities

This paper reflects upon the growing narrative research with people with intellectual disabilities. In this paper we consider some of the unexpected, hidden, elusive consequences of our quests for narratives with people with intellectual disabilities. In this paper we respond to Bourdieu's invitation to reflexivity in an attempt to unpack some of the complexities and power relations of research. We reflect on some of our own narrative work with people with intellectual disabilities. Our attention is not solely drawn to issues of method, but also highlights the ways in which we understand the narratives we collect and the narrators we work with. We also explore how our narrative work has potentially contributed to the construction of the label of intellectual disability. Our conclusion is that reflexivity is fundamental to research collaboration with people with intellectual disabilities. And attention should be paid to the strategies that people with intellectual disabilities employ in their resistance to prejudice and lack of power they experience in their daily lives.

Keywords: Intellectual disability, narratives, disability studies, reflexivity

INTRODUCTION

Narrative and life history approaches have a long history in social and human sciences. They are particularly useful when applied to recover the stories and voices of people who previously had been silenced and made invisible in history and society. Plummer´s phrase, 'tales of the outcast, the marginal and the silenced', captures this well (2001a, p. 91). Examples of these included an increased interest in women's autobiographies and narratives of slaves in North America in the 19th century. By the mid-20th century, this interest expanded and included the recognition of the voices of other marginalized groups in the form of lesbian and gay narratives and the stories of disabled and colonized people (Plummer, 2001a).

In the 1960s there was questioning 'of the legitimacy of official and institutional cultural authorities' (Gerber, 1990, p. 3). In that social and historical context, traditional research which treated people with intellectual disabilities as passive subjects increasingly aroused criticism (Whittemore, Langness and Koegel, 1986). A growing body of narrative literature suggests that people with intellectual disabilities have important stories to tell and can, with appropriate support, take part in research as collaborators and narrators. These studies have contributed to the growing plethora of oral histories, stories, accounts, personal perspectives, narratives, and vignettes associated with the study of intellectual disabilities (e.g., Atkinson, 2004; Carson and Docherty, 2002; Goodley, 1996, 1999, 2000; Johnson and Traustadóttir, 2005; Walmsley, 2002). Furthermore, research over the past few decades has brought the perspectives of disabled people into research, practice and policy related to the amelioration of the exclusion of people so labelled (Barnes, Barton and Oliver, 2002). This new strand of disability research criticizes traditional research for colonizing disabled people's lives and experiences, as well as non-disabled professionals for claiming authority over disabled people's needs. Scholars (e.g., Atkinson, 1997; Rappaport, 1995) have also brought attention to the risk of iterate negative stereotypes of victimization by selecting narratives of exclusion and discrimination while developing an auto-biographical research approach. This calls for reflexive research practices that attempt to unpack some of the complexities and power relations of research and shed some light on the consequences of this research; these consequences may not have been initially envisaged (by the researcher) but still, nonetheless, they have a definite potency and significance.

This article responds to Pierre Bourdieu's invitation to reflexivity (e.g., Bourdieu and Wacquant, 1992, p. 72). He asks that researchers take into account their presuppositions and how their cultural and social background influences their interpretation of the social world. In this article we reflect on some of our own narrative work with people with intellectual disabilities. Our attention is not solely drawn to issues of method, but also highlights the ways in which we understand the narratives we collect and the narrators we work with. Furthermore, we explore how our narrative work has potentially contributed to the construction of the label of intellectual disabilities.

THEORETICAL CONTEXT

This paper is collaboration between three researchers: one from Britain and two from Iceland. We address disability from a social perspective and reject the traditional bio-medical and individualistic understanding of disability. However, we locate ourselves in two distinct but related traditions. First, for two of us (Kristín and Hanna), the narratives we present from Iceland are understood and analysed within *the Nordic Relational Approach to Disability*. This is a common Nordic understanding of disability rather than a uniform approach and is characterized by the emphasis on relations between the environment and the disabled person (Traustadóttir and Kristiansen, 2004). The Icelandic narratives of intellectual disabilities are placed in a Nordic context where disability is understood as relational and caused by a discrepancy between

the disabled person's capabilities and the functional demands made by society which does not assume the full range of human diversity. A person is, therefore, defined as disabled if s/he confronts barriers in everyday life due to limited ability, diseases or impairment (Tøssebro, 2002, 2004). Disability is also viewed as situational rather than as an always-present essence of the person; for example, a person can be perceived as having intellectual disabilities in some situations and not in others (Tøssebro, 2002, 2004).

Second, the narratives from the UK (introduced by Dan) are understood from a British disability studies perspective. The discussion about disability refers to people who have the ascribed identities of 'disability'. Such a term of identity includes various people who have been historically situated in a myriad of impairment groupings including physical and sensory impairments, intellectual disabilities and people with mental health issues. A British disability studies stance endeavours not to embrace impairment specific considerations – as have many charities and organizations *for* disabled people – but instead considers disabled people as a heterogeneous group, with many impairment labels who face a number of overlapping experiences of exclusion or disablement. The disability studies perspectives are sometimes described as emancipatory disability studies. This concept is tied to the development of the disabled people's movement and many of the writers within the field are themselves disabled activists and 'organic intellectuals' in Gramsci's sense of this term (Oliver, 1990). Crucial to the development of British disability studies has been the ubiquitous use and reuse of the term *the Social Model of Disability* which has turned attention away from a preoccupation with people's impairments. Instead the focus has been on the ways in which disability is created through the social, economic, political, cultural, relational and psychological exclusion of people with impairments (Barnes, 1991; Oliver, 1990, 1996; UPIAS, 1976).

Although our research practices and theoretical interpretations on impairment and disability are rooted in a social perspective, we also draw from other theoretical work to inform our analysis and assist with our reflection. These include Bakhtin's (1965/1984, 1994, 2005) notion of the carnival; Bourdieu's (Bourdieu and Wacquant, 1992) cultural trajectory and legitimate power; and Deleuze and Guattari's (1987/2004) celebration of nomadic subjectivity. We build on these ideas when reflecting on the growing body of narrative research conducted with people with intellectual disabilities.

BEHIND THE CANON OF NARRATIVE RESEARCH

One of the pioneers in transforming research about people with intellectual disabilities was the American scholar Robert E. Edgerton with his study *The cloak of competence: Stigma in the lives of the mentally retarded* (1967). Although the study was ground-breaking at the time, in recent years attention has been drawn to the lack of authority given to participants' voices on the representation of their experiences by others (Gerber, 1990). Bogdan and Taylor's (1976) work marked a shift in research with people with intellectual disabilities, which placed emphasis on understanding how 'people

construct their realities, and the impact that the construction of mental retardation as a label has on these realities' (Klotz, 2004, p. 97).

These colleagues from the USA have influenced work in the UK as well as in Iceland. Although autobiography is quite popular in Icelandic society and central to the culture, narrative research with people with intellectual disabilities is relatively new with a growing number of researchers taking up collaborative narrative research projects with groups and individuals with intellectual disabilities. These projects include stories of parents with intellectual disabilities and their adult children (Sigurjónsdóttir, 2005; Sigurjónsdóttir and Traustadóttir, 2001) and narratives of people who lived for a long period of time in institutions for people with intellectual disabilities, but now live in mainstream society (Stefánsdóttir, 2008, 2010) and young adults who belong to the integration generation (Björnsdóttir, 2009).

In the UK, there have been many examples of narrative work with people with intellectual disabilities. The stories that people with physical impairments have written about disability from their own perspective as well as the accounts of people with intellectual disabilities have clarified the socially constructed nature of disability (e.g., Cheston, 1994; Deacon, 1974; Hunt, 1967; Oswin, 1991; Potts and Fido, 1991). The narrative approach employed by British scholars, such as Atkinson (1997) and Booth and Booth (1994, 1998a, 1998b) has gained much attention and has informed later work in this area (e.g. Goodley; 2000; Jahoda, Wilson, Starker and Cairney, 2010; Tilley, Walmsley, Earle and Atkinson, 2012).

There is a growing emphasis on equalization of power relationships and collaboration between people with intellectual disabilities and non-disabled researchers (e.g., Björnsdóttir and Svensdóttir, 2008; Boxall, Carson and Docherty, 2004; Docherty, Hughes, Phillips, Corbett, Regan, Barber et al., 2005; Hreinsdóttir, Stefánsdóttir, Lewthwaite, Ledger and Shufflebotham, 2006; McDonald and Kidney, 2012; Roets and Goedgeluck, 2007; Stefánsdóttir, 2008; Stefánsdóttir and Hreinsdóttir, 2013). This participatory approach values people with intellectual disabilities as collaborators or co-researchers and has strong ties to the disabled people's movement and the overall development of the field of disability (Walmsley, 2001).

FIVE STORIES BEHIND THE QUEST FOR TALES AND LIVES

In the following, we present five stories that have emerged from our narrative research practices. In several research projects with people with intellectual disabilities we have gathered narrative material through interviews and participant observations in various social activities, such as in self-advocacy groups, personal events, and leisure activities. We have constructed these narratives in collaboration with the narrators and most of the analysis has been done through conversations with each collaborator. By spending considerable amount of time with our collaborators we were able to become familiar with their values and more aware and sensitive to their wishes. But we also became aware of our interpretations and (sometimes) presumptions and the inclusive quality of our research made it possible for our collaborators to influence our research practices.

The stories we present, we have come to understand as oppositional, expected, disrupted, de/territorializing and carnivalesque. We tell these stories about our interactions with our collaborators in order to reflect upon a number of important considerations raised by these encounters. In particular, we want to draw attention to the power relations and assumptions that exist inside and outside of the canon of narrative intellectual disability research.

The oppositional story

This story takes place in Iceland when I (Kristín) was writing a life history in collaboration with Gunnar (pseudonym, as other names of participants in the article), who at the time was in his twenties and labelled as having intellectual disabilities. He participated in my doctoral research during the years of 2006 and 2007. I decided to introduce him to *photovoice,* which is a research method where photographs are used to gain understanding about people's lives and experiences. Participants use cameras to take pictures of places, people, and events, and through photographs they can depict their world or situation. Booth and Booth (2003) used this method with mothers with intellectual disabilities and claimed that the *photovoice* method offered an insight both into the individual lives and collective experiences of these mothers as a group. While most people rely a great deal on the written and spoken language in their narratives, many people with intellectual disabilities use alternative modes of communication, such as symbols, signs, and pictures. Therefore, I was optimistic that the *photovoice* method would be useful in our collaboration and by using a camera Gunnar would be able to communicate to me the various aspects of his life he found relevant to our pursuit for social change.

Gunnar is a national and international swimming champion. I was interested in learning about his life and how the sport hero was represented in his stories. He showed the *photovoice* method interest, but did not take any pictures on the disposable camera I provided. I assumed it was because he could not operate it. I focused on his impairment and accepted the deceptive medical label of intellectual disabilities. This label describes intellectual disabilities as an absolute condition and defines people as unintelligent and incompetent (Bogdan and Taylor, 1994). It did not cross my mind that Gunnar had actually used a different camera; his own, state of the art, digital camera. By refusing to use the disposable camera, Gunnar challenged my preconceived notions of his competencies and the label of intellectual disabilities. I was focused on his identity as a sport hero and overlooked the reality of his flux multiple identities. Gunnar did not only view himself as a triumphant swimmer; he also considered himself to be an artist and a skilled photographer. With his digital camera he frequently took family photos as well as artistic scenic photographs and he was not satisfied with the quality of the photos from the disposable camera.

We spent some time going through Gunnar´s photo albums and he told stories about family gatherings, holidays, and sporting events which provided a further insight into his life and experiences. I saw a new side to his life and learned much I had not expected from the stories. In his narratives and by refusing to use the disposable

camera, Gunnar took on an active oppositional position in our research collaboration. He did not take on the role of the passive research subject and challenged the label of intellectual disabilities as an absolute medical condition.

I brought with me to this research assumptions about Gunnar's abilities and I based these assumptions on the deficit or medical model of disability and as such looked for deficits in his performance. My attention was, in the process, diverted from his abilities and the true story of his life. I followed in the footsteps of those researchers who have, over the past couple of decades, been criticised by disabled people and disability study scholars alike for misrepresenting disabled people's lives and upholding negative and medical views on disability and impairment. The unexpected nature of this story relies on a researcher's deficit view of the person s/he is working with. This raises questions about attempts to promote, for example, inclusive research to counteract researchers assuming in/abilities and lack of capacity on the part of narrators. Before spending time with Gunnar and learning his story and background, I would not have been able to recognise his resistance or hear his unexpected and oppositional stories of achievement and abilities.

The expected story

Disability, just like parenthood and gender, is a socially constructed phenomenon that is located within and derives its meaning from specific cultural and temporal contexts. How disability is defined affects people's communications and expectations; similarly, stereotypes and labels affect how disabled people are perceived and treated.

This is the story about how I (Hanna), like others, was influenced by cultural images of both parenthood and people with intellectual disabilities. The dominant discourse obstructed my view and without realizing it I became a victim of my own prejudices. It was in 1994 when, as an undergraduate student, I was conducting my first qualitative study. This project was about the life and situation of Stella, a woman my age with intellectual disabilities who had travelled all over the world both as an athlete and as a self-advocate that gave talks on disability rights issues. I wanted to understand how she felt playing these two different roles as a devalued person with intellectual disabilities on the one hand and on the other as a highly valued athlete by international standards, as well as a disabled activist. I was primarily interested in her leadership as an self-advocate and athlete but when she told me her life story I learnt that she had recently been forced by her family to undergo an abortion and was still wounded emotionally as a result of that experience. I listened to her telling me this without 'hearing' or realizing what she was actually saying. With my focus on the research topic and the 'story' I expected to hear, I kept asking her questions about her different roles in life. It was not until the next day when I was transcribing the interview that I heard and understood what she had been telling me. I felt ashamed but also surprised that I had missed this in the interview situation itself. Furthermore, I was taken aback because until then it had never occurred to me that women with intellectual disabilities might want to become pregnant, be mothers or even have sex. I also did not know that mothers with intellectual disabilities even existed.

Looking back I realized that I had seen Stella through the lens of cultural stereotypes that portray women with intellectual disabilities as both childish and asexual. These widely held societal assumptions and beliefs are firmly grounded in the individual deficit model of thinking which locates the 'problem' within the individual (Atkinson, 1997; Shakespeare, 1996; Sonnander, 2005; Tideman, 2005). Although we were the same age, and I was a young mother and wife at the time, I did not expect Stella to have access to the same roles in life as I did as a mother and sexual being. This is in accordance with Jean Baker Miller (1978) and Wolf Wolfensberger (1972) who have described how the most highly valued roles in society are connected to the dominant groups and it is taken for granted that devalued people would not be able to carry them out.

This story is a good example of how the social construction of disability takes place in the relations between different individuals (Gustavson, Tøssebro and Traustadóttir, 2005). My reaction reflects the prevailing negative cultural stereotypes of how people with intellectual disabilities are affected by the way they are seen and treated; further, it demonstrates how disabling the dominant discourse can be. And through the lenses of the social understanding of disability I was able to understand the role of society or dominant discourse of shaping Stella's life and experiences as well as my interactions with her as a woman labelled as having intellectual disabilities.

The disrupted story

This story is another account of Kristín's interactions with participants in her doctoral research (2006–2007). Anna, like Gunnar, is a nationally accomplished swimmer and I was very interested in her stories about travelling to different places with her swim club, but Anna only wanted to talk about her high school years. When we started our collaboration I knew beforehand that she was an athlete. I was looking forward hearing about her participation in various sporting events, but Anna told me different and unexpected stories instead (Cary, 1999).

Narrative research is constructed through the interactions between the narrator and the interviewer and by telling her story the narrator reconstructs her life and identity (Denzin, 1984b). Anna resisted my questions and probes about sport meets and kept returning to the topic of her upper secondary education. I was not interested in issues concerning education and tried to persuade her to tell me the story I wanted to hear. Fortunately, Anna was not easily persuaded, and I finally 'allowed' her to tell me her story and as it turned out it had much to do with my initial question about her participation in sporting events. At the special school she did not take any English classes. She was upset about that because her poor English skills limited her opportunities to participate in many social activities. For example, she could not go to the movies if the film had a complicated plot[1] and she could not use the Internet since most of it is in English. Anna also had difficulties communicating with people from different countries at all the international sporting events she had participated in. She could not understand them and felt embarrassed and disappointed because these events are not merely about competing it is also about socializing – meeting new people and making new friends.

In narrative research the narrator tells the stories she thinks are biographically important at that particular time in her life (Denzin, 1984b). Anna told the story she felt people should hear and my initial response was that she was disrupting the research process, *my agenda* and the aims of *my project* when in fact it was I, the researcher, who was disrupting her story. This draws our attention to ethical issues of ownership and authenticity (Denzin, 1984a; Plummer, 2001b). Anna was not interested in getting involved in the research process like data analysis, presenting papers at conferences and contributing to published research findings. Therefore, the research output was my interpretation of our interactions and her lived experiences. By locating Anna's personal story in time and space and placing it into a cultural context I reconstructed it as narrative research (Goodson, 2005). And by doing so I am adding to the knowledge of a group I am not a member of, contributing to the construction of the *Other*, and I am at risk of colonizing Anna's story – particularly if and when my questions and interests do not match those of Anna's (Fine and Weis, 1996; Goodson, 2005; Traustadóttir 2001).

Historically, disabled people's voices have been left out of the discussion on impairment and disability and have had less legitimacy and authority than the opinions of professionals on the issue of disability (Gerber, 1990). Although disabled people are now increasingly being involved in the research process and researchers examine their power through reflexivity (Finley, 2002; Traustadóttir, 2001), stories are still being silenced, misunderstood, dismissed, and discarded.

The de/territorializing story

So far we have looked at the processes in and out of the doings of narrative research, but what of our attempts to understand and analyse stories? The following account is taken from a conference attended by Dan in 2006, which was one of the first conferences to promote self-advocacy in a specific Asian country. During the conference, attended by over 120 delegates, including self-advocates, their supporters, parents, NGOs, professionals and researchers, members of self-advocacy groups from across the nation made presentations about the importance of self-advocacy. Following one presentation by a man I shall call Samuel his mother jumped up from her seat and addressed the conference:

> You (pointing at author), people like you, see what you have done to my LD son (sic). You talk of rights, of speaking up for yourself and you hear him now, talking as if he had no respect for me or his father. My LD son will never be able to live independently, but you fill his head with nonsense. You should be ashamed.

As chair of the session, I started to respond to her worries but stopped when I saw Samuel carefully walking from his seat to the microphone and lectern at the front of the room. He spoke quietly but with passion:

> I will live independently. I do now. With my colleagues at the self-advocacy groups. They help me and I help them. I must remind all of you here, conference, that we are strong and are getting stronger. Thank you.

As the applause resonated from the delegates, as Samuel spoke sadly about his mother's words and later when Samuel's mother refused to shake my hand, I was reminded of the real struggles and conflicts experienced on a daily basis by many adults with intellectual disabilities. Read from an insider perspective (see Moore, 2000), this story could be viewed as a clash of ambitions and perspectives so typical of the lack of match between self-advocates and their parents (Mitchell, 1998). Clearly, we have to decide whose side we are on here, and for many this would mean aligning ourselves with Samuel from a disability studies perspective. The story is read, one narrator over another, as: the son seeking independence from an over protective mother; a clash of agendas; parent-child; disabled-non-disabled. Read in another way, we may more closely appreciate the complexities of human subjectivity and Samuel and his mother's toils with these complexities.

The writings of Deleuze and Guattari (1987/2004) are helpful here, particularly the associated analyses developed by Allan (2004), Braidotti (1994), Roets and Goedgeluck (2007) and Roets, Reinaart, Adams and Van Hove (2008). A Deleuzoguattarian analysis views struggles for personhood not in terms of siding with a particular person, subject or storyteller but as dynamic journeys across territories by human subjects who are constantly nomadic in their travels. For Braidotti (1994), the nomad is involved in transitions and passages, often uncertain and perhaps without pre-determined destinations or lost homelands. Nomadism refers to the kind of critical consciousness that resists settling into socially coded modes of thought and behaviour. The idealized place for nomadism is a smooth desert: a go game, devoid of limitations, strata and the blockages of creativity (see also, Goodley 2007). Hence, while Samuel's mother attempts to territorialize her son's life in ways that might be seen as protective and containing – perhaps overcoding at times – Samuel (her fellow traveler) offers ways of deterritorialising her landscapes and reterritorialising other landscapes where possible locations include self-advocacy. The sense here, then, is of two travellers finding and refinding new lands: we should always 'have a small plot of new land at all times' (Deleuze and Guattari, 1987/2004, p. 178). Never settle, but move and continue. To freeze the story, as I have above, leads to the danger of reading Samuel as an activist and his mother as a protector. Alternatively, the analysis offered here allows us to think of the story as a dynamic process: of dropping old and always finding new lands.

The carnivalesque story

My (Kristín's) doctoral research project consisted of a combination of ethnographic methods and narrative inquiry. Spending time with participants brought me closer to them and altered the power relations. It also helped me to understand how people use different ways of communication. Their storytelling was not always through the traditional modes of narrating and was often misunderstood by me and by others (family, friends and carers).

I volunteered as a camp leader at a weeklong European 'youth camp' for young adults with intellectual disabilities in Denmark in 2006. I was supposed to support

five Icelanders who had been chosen by a local organization to attend this camp. I had little information about this project, the people who I was supporting, and my role as a camp leader. One of the women in the group was Sara, a participant in my research. Being able to spend more time with her was the reason for me volunteering. She is a gifted singer and actress and has appeared nationally in movies, on TV shows and in concerts. Sara is great fun to be around but some people might get annoyed with her habit of imitating and mimicking the people around her. One day I was sunbathing on a beach in Denmark and Sara walked up to me and asked what I was doing. I told her I was enjoying the good weather. Then Sara responded by telling me it was not an option to sunbathe on the beach. I was surprised and Sara laughed and said: 'It is what you tell me all the time. It is not an option.' She was spot on because I had been bossing her around during our stay in Denmark. I had been telling her to put on a sweater because the weather was cold, telling her to eat her dinner even though she did not like the food, and telling her to go to bed early because I was tired and needed sleep. Her imitation of me was not simply an annoying habit, but a powerful way of narrating her experience of our interactions.

It is interesting to look at our interactions in the context of Bakhtin's (1965/1984) idea of the carnival laughter. He draws on the medieval carnival where power structures are inverted and the world is turned upside down: 'A boundless world of humorous forms and manifestations opposed the official and serious tone of medieval ecclesiastical and feudal culture' (Bakhtin, 1994, p. 196). The humour and laughter is important in the carnival also when the purpose is satire (Bakhtin, 2005). Sara used it to question my authority as a camp leader and she made fun of my behaviour and position. She was not simply mocking me personally, but also the power structures of the camp where non-disabled leaders have the power and authority to tell *Others*, adult participants with intellectual disabilities, what to do and how to behave. She used the carnival laughter to challenge 'traditional concepts of logic and identity' (Glazener, 1989, p. 159).

My actions reflect our power relations where I hold power over Sara simply because I am non-disabled and I justify these relations, or in Bourdieu's (Bourdieu and Passeron, 1990) terms, legitimate them on the basis of caring. It is not for what our power relations really are, but for what I have perceived them and legitimized them to be (Bourdieu, 1982/1991). I take part in reproducing the arbitrary non-disabled position as dominant over disabled people. And that raises questions about power relations in research and how researchers, often in good faith, assert power as experts on other people, the disabled participants. Our interactions and Sara's outbursts of carnivalesque laughter show that even though all research is itself a constitution of power relations, they may shift and change.

DISCUSSION: REFLECTIONS ON NARRATIVE RESEARCH

The research encounters described above demonstrate the powerful positions of researchers and their assumptions while also indicating that narrators are not simply

passive respondents. To understand our practices and suppositions, it is useful to draw from the ideas of the French sociologist Pierre Bourdieu. From early childhood social actors develop attitudes and dispositions that unconsciously steer their practices and are in a way produced by their social history or what Bourdieu (1994) refers to as 'cultural trajectory'. We (the authors of this article) are sidetracked by our 'cultural trajectory', which is grounded in the grand theoretical narrative of disability and attempts to give an absolute explanation of disabilities and ignores the complexity of living with and negotiating impairment. The grand theory of disability could further be explained in the terms of a grand theoretical narrative of pathology or deficits which serves the purpose of determining the individual's limitations and inabilities (Thomas, 2008). The grand theoretical narrative is deeply grounded in medicine, diagnostics, developmental psychology, and special education and has shaped services for disabled people that consist of exclusion and marginalization. The grand theoretical narrative influences all society, not only such fields as disability and academia. For example, in an analysis of Icelandic print media, Kristín identified that the discourse in newspapers and magazines is dominated by a defective understanding of disability and people with intellectual disabilities are presented as childlike, dependent and incompetent (Björnsdóttir and Jóhannesson, 2009).

By responding to the call for research reflexivity and reflecting on the complex relationships in intellectual disabilities research through the lenses of social approaches, *the Nordic Relational Approach and the British Social Model*, we are reminded how easily we can be sidetracked by the grand theoretical narrative of disability. Although we belong to the field of disability studies, contributing to the new social understanding of disability and engaging in participatory research, we still produce misconceptions shaped by the grand theoretical narrative.

Our collaborators' experiences are also influenced by the grand theory. They have been labelled by the medical, social, and educational systems as having intellectual disabilities. They have been grouped with people who are generally considered incompetent and childlike. Their 'social trajectory' is one of discrimination, exclusion, and marginalization. Looking back at the oppositional and disrupted stories told above, the question of anticipation is raised; do they anticipate our disabling assumptions? If we look at the interactions between Kristín and her collaborators we see them negotiating their disability by challenging and resisting preconceived notions of their competencies. The negotiation is rooted in a counter narrative of disability that challenges the dominant and disabling grand narrative. The counter narrative arises from the disability movement and self-advocacy of disabled people around the globe. It is in opposition to the dominant deficit understanding of disability and in line with the rise of the new academic field of disability studies, where social understandings of disability are being developed, including *the Nordic Relational Approach and the British Social Model*. The grand theoretical narrative is constructed and reproduced by professionals who are trained to diagnose, teach, train, and care for disabled people. Historically, people with intellectual disabilities have been excluded and marginalized from participation in society and their voices have been unheard. Therefore, people with intellectual disabilities have not had opportunities to contribute to the construction

of the grand narrative of disability, which makes the counter narrative important in battling exclusion and disabling views (Stefánsdóttir, 2008).

An overemphasis on our power and influence as researchers should also be avoided. This runs the risk of underestimating the power possessed by the narrators, and in turn, reproduces the grand theory whereby people with intellectual disabilities are rendered as passive, incompetent and easily manipulated. In our experience, people with intellectual disabilities are able to subvert the conditions of research, even when the researchers' views or those of significant others are belittling.

Despite the best interest and efforts to make intellectual disabilities research participatory and inclusive there seems to be a tendency to underemphasize how these studies and narratives add to the construction of the label of intellectual disabilities. Bogdan and Taylor (1994) reject the idea of intellectual disabilities (or 'mental retardation' as they call it) as an absolute condition and claim that it is socially constructed. They argue that the label is associated with stigma and people labelled as intellectually disabled are at risk of being viewed as deviant and consequently rejected by society. Keeping that in mind it seems relevant to be aware of our contribution, as researchers, to the construction or deconstruction of this label that has historically been viewed in negative terms. This brings us back to Dan's story about deterritorialising and reterritorialising relationships between a self-advocate with intellectual disabilities and his mother. As researchers and advocates, we need to question our decisions about how we tell these stories, where we decide to freeze the picture and how that decision influences the construction of intellectual disabilities and iterates or opposes the grand theoretical narrative. Perhaps we can never fully escape the seductive powers of the grand theory, but by engaging in reflexivity and continually questioning and challenging our practices, in collaboration with our narrators, we might be able to contribute to a more inclusive construction of the humanity of people with intellectual disabilities.

Concluding Remark

If we look carefully enough we can see how narrative research collaboration between people with intellectual disabilities and academic researchers can produce further stories, accounts, perspectives, and understandings. Even by employing critical and inclusive research approaches we are always at risk of promoting disabling views of people with intellectual disabilities through the impact of our presuppositions. We have been collaborating with people with intellectual disabilities for over 15 years and have learned how committing to inclusive practices enables us to look again at the research process and, equipped with appropriate theoretical tools and analytical lenses, seek out the ways in which people with intellectual disabilities challenge exclusionary constructions of their humanity. We have come to understand the importance of asking questions about how people with intellectual disabilities want to be presented and that we should not underestimate their abilities to resist our presuppositions and power position as researchers. Although the primary goal of our research is to add to the knowledge of the lives of people with intellectual disabilities for the purpose of

improving their position in society, it is also important to take part in deep interrogation of the processes, possibilities and potentials that exist in narrative research with people with intellectual disabilities.

NOTE

Most films in Icelandic movie theatres are foreign with Icelandic sub-titles.

REFERENCES

Allan, J. (2004). Deterritorializations: Putting postmodernism to work on teacher education and inclusion. *Educational Philosophy and Theory, 36*(4), 417–432. doi:10.1111/j.1469-5812.2004.00078.x

Atkinson, D. (1997). *An auto/biographical approach to learning disability research*. Aldershot: Ashgate.

Atkinson, D. (2004). Research and empowerment: Involving people with learning difficulties in oral and life history research. *Disability and Society, 19*(7), 691–702. doi:10.1080/0968759042000284187

Bakhtin, M. (1984). *Rabelais and his world* (H. Iswolsky, trans.). Bloomington: Indiana University Press. (Original work published 1965).

Bakhtin, M. (1994). Carnival ambivalence. In P. Morris (Ed.), *The Bakhtin reader: Selected writings of Bakhtin, Medvedev, Voloshinov,* (pp. 206–225). London: Arnold publishers.

Bakhtin, M. (2005). *Orðlist skáldsögunnar:* Úrval *greina og bókakafla.* [The discourse of the novel: Selected writings by Mikhail Bakhtin] (J. Ólafsson, trans.). Reykjavík: Institute of Research in Literature.

Barnes, C. (1991). *Disabled people in Britain and discrimination: A case for anti-discrimination legislation*. London: C. Hurst.

Barnes, C., Barton L. and Oliver, M. (Eds.). (2002). *Disability studies today.* Cambridge: Polity Press.

Björnsdóttir, K. (2009). *Resisting the reflection: Social participation of young adults with intellectual disabilities* (Unpublished doctoral dissertation). University of Iceland, Reykjavík.

Björnsdóttir, K. and Svensdóttir, A. S. (2008). Gambling for capital: Learning disability, inclusive research and collaborative life histories. *British Journal of Learning Disabilities, 36*(4), 263–270. doi:10.1111/j.1468-3156.2008.00499.x

Björnsdóttir, K. and Jóhannesson, I. Á. (2009). People with intellectual disabilities in Iceland: A Bourdieuean interpretation of self-advocacy. *Intellectual and Developmental Disabilities, 47*(6), 436–446. doi:10.1352/1934-9556-47.6.436

Bogdan, R. and Taylor, S. (1976). The judged, not the judges: An insider's view of mental retardation. *The American Psychologist. 31*(1), 47–52.

Bogdan, R. and Taylor, S. (1994). *The social meaning of mental retardation: Two life stories.* New York: Teachers College Press.

Booth, T. and Booth, W. (1994). *Parenting under pressure: Mothers and fathers with learning difficulties.* Buckingham: Open University Press.

Booth, T. and Booth, W. (1998a). *Advocacy for parents with learning difficulties: Developing advocacy support.* Brighton: Pavilion.

Booth, T. and Booth, W. (1998b). *Growing up with parents who have learning difficulties.* London: Routledge.

Booth, T. and Booth, W. (2003). In the frame: Photovoice and mothers with learning difficulties. *Disability and Society, 18*(4), 431–442. doi**:**10.1080/0968759032000080986

Bourdieu, P. (1982/1991). *Language and symbolic power* (G. Raymond and M. Adamson, trans.). Cambridge: Harvard University Press. (Original work published 1982).

Bourdieu, P. (1994). *The field of cultural production.* Columbia: Columbia University Press.

Bourdieu, P. and Passeron, J. C. (1990). *Reproduction in education, society and culture* (2nd *ed*.). London: Sage.

Bourdieu, P. and Wacquant, L. J. (1992). *An invitation to reflexive sociology.* Chicago: The University of Chicago Press.

Boxall, K., Carson, I. and Docherty, D. (2004). Room at the academy? People with learning difficulties and higher education. *Disability and Society, 19*(2), 99–112. doi:10.1080/0968759042000181749

Braidotti, R. (1994). *Nomadic subjects: Embodiment and sexual difference in contemporary feminist theory.* New York: Columbia University Press.

Carson, I. and Docherty, D. (2002). Friendships, relationships and issues of sexuality. In D. G. Race (Ed.), *Learning disability: A social approach,* (pp. 139–153). London: Routledge.

Cary, L. J. (1999). Unexpected stories: Life history and the limits of representation. *Qualitative Inquiry, 5*(3), 411–427. doi:10.1177/107780049900500307

Cheston, R. (1994). The accounts of special education leavers. *Disability and Society, 9* (1), 58–69. doi:10.1080/09687599466780051

Deacon, J. J. (1974). *Tongue tied.* London: National Society for Mentally handicapped Children.

Deleuze, G. and Guattari, F. (1987/2004). *A thousand plateaus. Capitalism and schizophrenia.* London: Continuum. (Original work published 1987).

Denzin, N. K. (1984a). *Interpretive biography.* London: Sage.

Denzin, N. K. (1984b). *On understanding emotion.* San Francisco: Jossey Bass.

Docherty, D., Hughes, R., Phillips, P., Corbett, D., Regan, B., Barber, A. et al. (2005). This is what we think. In D. Goodley, D. and G. Van Hove (Eds.), *Another disability studies reader: People with learning disabilities and a disabling world,* (pp. 27–50). Antwerpen: Garant.

Edgerton, R. (1967). *The cloak of competence: Stigma in the lives of the mentally retarded.* Berkeley: University of California Press.

Fine, M. and Weis, L. (1996). Writing the 'wrongs' of fieldwork: confronting our own research/writing dilemmas in urban ethnographies. *Qualitative Inquiry, 2*(3), 251–274. doi:10.1177/107780049600200301

Finley, L (2002). Negotiating the swamp: The opportunity and challenge of reflexivity in research practice. *Qualitative Research 2*(2), 209–230. doi:10.1177/146879410200200205

Gerber, D.A. (1990). Listening to disabled people: The problem of voice and authority in Robert B. Edgerton´s The Cloak of Competence. *Disability, Handicap and Society, 5*(1), 3–23.

Glazener, N. (1989). Dialogic subversion: Bakhtin, the novel and Gertrude Stein. In K. Hirschkop and D. Shepherd (Eds.), *Bakhtin and cultural theory,* (pp. 155–176). Manchester: Manchester University Press.

Goodley, D. (1996). Tales of hidden lives: A critical examination of life history research with people who have learning difficulties. *Disability and Society, 11*(3), 333–348. doi:10.1080/09687599627642

Goodley, D. (1999). Disability research and the 'Researcher template': Reflections on grounded subjectivity in ethnographic research. *Qualitative Inquiry, 5*(1), 24–46. doi:10.1177/107780049900500102

Goodley, D. (2000). *Self-advocacy in the lives of people with learning disabilities: The politics of resilience.* Buckingham: Open University Press.

Goodley, D. (2007). Becoming rhizomatic parents: Deleuze, Guattari and disabled babies. *Disability and Society, 22*(2), 145–160. doi:10.1080/09687590601141576

Goodson, I. (2005). *Curriculum, pedagogy and life works: The selected works of Ivor Goodson.* Oxon: Routledge.

Gustavson, A., Tøssebro, J. and Traustadóttir, R. (2005). Introduction: Approaches and perspectives in Nordic disability research. In A. Gustavsson, J. Sandvin, R. Traustadóttir and J. Tøssebro (Eds.), *Resistance, reflection and change: Nordic disability research,* (pp. 23–44). Lund: Studentlitteratur.

Hreinsdóttir, E., Stefánsdóttir, G. V., Lewthwaite, A., Ledger, S. and Shufflebotham, L. (2006). Is my story so different from yours? Comparing life stories, experiences institutionalization and self-advocacy in England and Iceland. *British Journal of Learning Disabilities, 34*(3), 157–166. doi:10.1111/j.1468-3156.2006.00417.x

Hunt, N. (1967). *The world of Nigel Hunt: The diary of mongoloid youth.* Beaconsfield: Darwen Finlayson.

Jahoda, A., Wilson, A., Stalker, K. and Cairney, A. (2010). Living with stigma and self-perceptions of people with mild intellectual disabilities. *Journal of Social Issues, 66*(3), 521–534. doi:10.1111/j.1540-4560.2010.01660.x

Johnson, K. and Traustadóttir, R. (Eds.). (2005). *Deinstitutionalization and people with intellectual disabilities: In and out of institutions.* London: Jessica Kingsley.

Klotz, J. (2004). Sociocultural study of intellectual disability: Moving beyond labelling and social constructionist perspectives. *British Journal of Learning Disabilities, 32*(2), 93–104. doi:10.1111/j.1468-3156.2004.00285.x

McDonald, K. E. and Kidney, C. A. (2012). What is right? Ethics in intellectual disabilities research. *Journal of Policy and Practice in Intellectual Disabilities, 9*(1), 27–39. doi:10.1111/j.1741-1130.2011.00319.x

Miller, J. B. (1978). *Toward a new psychology of women.* Harmondsworth: Penguin Books.

Mitchell, P. (1998). *Families and self-advocacy* (Unpublished doctoral dissertation). Open University, Milton Keynes.

Moore, M. (2000). *Insider perspectives on inclusion: Raising voices, raising issues*. Sheffield: Phillip Armstrong.

Oliver, M. (1990). *The politics of disablement*. Basingstoke: Macmillan.

Oliver, M. (1996). *Understanding disability: From theory to practice.* Basingstoke: Macmillan.

Oswin, M. (1991). *Am I allowed to cry? A study of bereavement amongst people who have learning difficulties*. London: Souvenir Press.

Plummer, K. (2001a). *Documents of life 2: An invitation to a critical humanism.* London: Sage.

Plummer, K. (2001b). The call of life stories in ethnographic research. In P. Atkinson, A. Coffey, S. Delamont, J. Lofland and L. Lofland (Eds.), *Handbook of ethnography,* (pp. 395–406). London: Sage.

Potts, M. and Fido, R. (1991). *A fit person to be removed*: *Personal accounts of life in a mental deficiency institution*. Plymouth: Northcote House.

Rappaport, J. (1995). Empowerment meets narrative: Listening to stories and creating settings. *American Journal of Community Psychology, 23*(5), 795–807.

Roets, G. and Goedgeluck, M. (2007). Daisies on the road: Tracing the political potential of our postmodernist feminist approach to life story research. *Qualitative Inquiry, 13*(1), 85–112. doi:10.1177/1077800406295624

Roets, G., Reinaart, R., Adams, M., and Van Hove, G. (2008). Looking at lived experiences of self-advocacy through gendered eyes: Becoming femme fatale with/out 'learning difficulties'. *Gender and Education, 20*(1), 15–29. doi:10.1080/09540250701763319

Shakespeare, T. (1996). Disability, identity and difference. In C. Barnes and G. Mercer (eds.), *Exploring the divide: Illness and disability,* (pp. 94–113). Leeds: The Disability Press.

Sigurjónsdóttir, H. B. (2005). Family support services and parents with learning difficulties (Unpublished doctoral dissertation). University of Sheffield, Sheffield.

Sigurjónsdóttir, H. B. and Traustadóttir, R. (2001). Ósýnilegar fjölskyldur: seinfærar/ þroskaheftar mæður og börn þeirra [Invisible families: Mothers with learning difficulties and their children]. Reykjavík: University of Iceland Press.

Sonnander, K. (2005). Biological and social aspects of intellectual disability. In A. Gustavsson, J. Sandvin, R. Traustadóttir and J. Tøssebro (Eds.), *Resistance, reflection and change: Nordic disability research,* (pp. 193–203). Lund: Studentlitteratur.

Stefánsdóttir, G. V. (2008). „Ég *hef svo mikið að segja": Lífssögur* Íslendinga *með* þroskahömlun *á 20.* öld ['I have so much to say': Life histories of Icelandic people with intellectual disabilities in the 20th century] (Unpublished doctoral dissertation). University of Iceland, Reykjavík.

Stefánsdóttir, G. V. (2010). Raddir fólks með þroskahömlun: Bernska og æskuár [The voices of people with intellectual disabilities: Youth and childhood]. *Tímarit um menntarannsóknir, 7*(1), 13–27.

Stefánsdóttir, G. V. and Hreinsdóttir, E. E. (2013). Sterlization, intellectual disability, and some ethical and methodological challenges: It shouldn´t be a secret. *Ethics and*

Social Welfare, 7(3), 302–308. doi:10.1080 / 17496535.2013.815792

Thomas, G. (2008, March). *Theory and the construction of pathology.* Paper presented at the American Educational Research Association, New York.

Tideman, M. (2005). A relational perspective on disability: An illustration from the school system. In A. Gustavsson, J. Sandvin, R. Traustadóttir and J. Tøssebro (Eds.), *Resistance, reflection and change: Nordic disability research,* (pp. 219–232). Lund: Studentlitteratur.

Tilley, E., Walmsley, J., Earle, S. and Atkinson, D. (2012). 'The silence is roaring': Sterilization, reproductive rights and women with intellectual disabilities. *Disability and Society, 27*(3), 413–426. doi:10.1080 / 09687599.2012.654991

Traustadóttir, R. (2001). Research with others: Reflections on representation, difference and othering. *Scandinavian Journal of Disability Research, 3*(2), 9–28. **doi:**10.1080 / 15017410109510773

Traustadóttir, R. and Kristiansen, K. (2004). Introduction. In R. Traustadóttir and K. Kristiansen (Eds.), *Gender and disability research in the Nordic countries,* (pp. 17–30). Lund: Studentlitteratur.

Tøssebro, J. (2002, August). *A brief introduction to 'the Nordic relational approach to disability'.* A working paper for the 6th NNDR annual conference, Reykjavik, Iceland.

Tøssebro, J. (2004). Introduction to the special issue: Understanding disability. *Scandinavian Journal of Disability Research, 6*(1), 3–7. doi:10.1080 / 15017410409512635

UPIAS (1976). *Fundamental principles of disability.* London: Author.

Walmsley, J. (2001). Normalisation, emancipatory research and inclusive research in learning disability. *Disability and Society, 16* (2), 187–205. doi:10.1080 / 09687590120035807

Walmsley, J. (2002). Principles and types of advocacy. In B. Gray and R. Jackson (Eds.), *Advocacy and learning disability,* (pp. 24–37). London: Jessica Kingsley.

Whittemore, R. D., Langness, L. L. and Koegel, P. (1986). The life history approach to mental retardation. In L. L. Langness and H. G. Levine (Eds.), *Culture and retardation: Life histories of mildly mentally retarded persons in American society,* (pp. 1–18). Dordrecht: Springer.

Wolfensberger, W. (1972). *The principle of normalization in human services.* Toronto: National Institute on Mental retardation.

ABOUT THE AUTHORS

Kristin Bjornsdottir (kbjorns@hi.is) has a B.M. in Music Therapy from East Carolina University. She received her Teaching Certification (Teaching Studies) from University of Iceland where she continued her studies and received a M.A. in Education with an emphasis on disability research and a Ph.D. in Disability Studies. Since 2003 she has been a teacher and a researcher at the Iceland University of Education and University of Iceland.

Dan Goodley (d.goodley@sheffield.ac.uk) teaches on the M.A. in Psychology and Education (which he also directs) and the B.A. Education, Culture and Childhood at the University of Sheffield. Dan is interested in Critical Disability Studies, theorising and challenging the conditions of disablism and ableism.

Hanna Bjorg Sigurjonsdottir (hbs@hi.is) has a Ph.D in Disability Studies from the University of Sheffield. She has M.A. and B.A. degrees in Education from the University of Iceland. Hanna Björg is an Associate Professor at the University of Iceland. Her main emphasis in teaching and research are disability related issues.