



Gambling for capital: learning disability, inclusive research and collaborative life histories

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Accessible summary

- This paper is about a partnership between a self-advocate with learning disabilities and a university student.
- We think it is important for people with learning disabilities to be involved in research as partners with university researchers.
- We think it is important for people with learning disabilities to have the opportunity to tell their story. We believe it can help others; both people with learning disabilities, carers and researchers.
- We think that people with learning disabilities are not taken seriously as researchers by university researchers.

Summary

The aim of this paper is to reflect on research collaboration between a research participant with learning disability and a nondisabled doctoral student. In the paper we explore the inclusiveness of our research partnership and how collaborative life histories can be empowering both for participants and researchers. We suggest that it is possible to make any kind of research inclusive, although doctoral projects can perhaps not be fully inclusive because of academic requirements. We argue that people with learning disabilities should have the opportunity to be involved in research and that collaborative writing between nondisabled researchers and people with learning disabilities is no less valuable than other disability research and should be taken seriously by policy makers and academia. A second aim of the paper is to reflect on our position, as a nondisabled researcher and a researcher with learning disabilities, in the field of disability studies. We state that as researchers we have little power in the field of disability studies because researchers with learning disabilities are not taken seriously and nondisabled researchers tend to be met with scepticism.

Keywords Collaborative life histories, cultural capital, disability studies, inclusive research, learning disability

Introduction

Traditionally much research addressing learning disabilities has been from the perspective of social workers, psychiatrists, psychologists and other professionals (Klotz 2004).

Also, research on the participation of people with learning disabilities in social activities has mainly focused on support and services. However, scholars like Ramcharan *et al.* (1997), Goodley (2000), Walmsley (2002), Atkinson (2002), Sigurjónsdóttir (2004), Johnson & Traustadóttir (2005) and

Boxall (2007) have emphasized the perspectives of individuals with learning disabilities. Disabled people themselves have underlined the importance of equal power relationship between disabled people and nondisabled researchers. That has led to more balanced collaboration and partnership between researchers and research participants and disabled people are now increasingly being involved in the research process (Traustadóttir 2006) and some attempts have been made to engage with inclusive research with people with learning disabilities (For example: Boxall *et al.* 2004; Carson & Docherty 2002; Chapman & McNutty 2004; Ham *et al.* 2004; Hreinsdóttir *et al.* 2006; Docherty *et al.* 2005; Johnson & Traustadóttir 2005; Mitchell *et al.* 2006; Roets *et al.* 2004; ESRC seminar series, 2007).

Walmsley & Johnson (2003) have identified 'inclusive research' as an approach to research that involves people with learning disabilities as active participants. In their view, inclusive research is closely related to participatory research (Chappell 2000; Park *et al.* 1993) and emancipatory research (Barnes 2004), the latter having strong connections with the British social model of disability and UK's disabled people's movement (Barnes 2004; Boxall *et al.* 2004). These research traditions allow for increased participation and power by disabled people over the research process as a whole with a common aim to improve disabled people's lives. Chappell (2000) argues that one of the main distinctions between participatory and emancipatory research lies in the relationship between disabled people and researchers. Emancipatory research is commonly accountable to disabled people and their organizations and disabled people are supposed to be in control of the research process (Barnes 2004). Participatory research on the other hand refers to relationships with individual participants instead of larger organizations of disabled people (Chappell 2000). The term inclusive research refers to both of these strands of research leaving behind the debate of methodological differences and inclusive researchers are influenced by ideas of normalisation where for example people with learning disabilities take on valued social roles as co-researchers (Walmsley 2001). Thus, although the practice of inclusive research is not widespread, it has strong ties to the disabled people's movement and is closely linked to some of the key concepts and developments in the field of disability over the past few decades.

This paper has two main objectives. First, to reflect on research collaboration between Aileen S. Svendsdóttir, a research participant with learning disabilities, and Kristín Björnsdóttir, a nondisabled doctoral student at the University of Iceland. We explore the inclusiveness of our research co-operation and how collaborative life histories can empower collaborators and research practice. The second objective is to reflect on our position, as a nondisabled researcher and a researcher with learning disabilities, in the field of disability studies by drawing on Bourdieu's sociology of culture.

The research project

The research project is a part of Kristín's doctoral research which focuses on the role of cultural factors in the experiences and social participation of young adults with learning disabilities with particular reference to gender and identity. Data collection for the study began in 2004 and is still ongoing. The collaborators in the study are young Icelandic adults with learning disabilities who were born in the years 1974–1984 and are actively involved in various social activities such as self-advocacy, sports, religion and arts. The project is based on six life histories and follows an inclusive research paradigm, that is, all participants are included as collaborators and are not viewed as merely research subjects (Walmsley & Johnson 2003). By becoming collaborators the participants have more power over the research process than traditional research approaches allow for. This includes power to accept and reject ideas and power regarding ownership. The participants told stories about their lives and invited Kristín to participate in various social activities with them. Also, three participants wanted Kristín to interview their friends and families. Two of the participants were actively involved in the research process as a whole undertaking data analysis, presenting papers at conferences, contributing to published research findings and taking on the role of co-researchers. One is Aileen S. Svendsdóttir who co-authors this paper.

Our research collaboration had lasted for little over a year when this was written. We first met about three years ago when Kristín was working on a project with Aileen's self-advocacy group - Átak. At the time, Aileen was the vice chairman of the self-advocacy group and had been an active self-advocate for six years. Since the PhD project focused on Aileen's main interests as a self-advocate she was interested in being actively involved in the research. She had been involved in research many times before and sometimes felt that it was not worth while. She had been treated as a source of data and in some instances did not have access to the research findings or see it lead to any changes for people with learning disabilities. Aileen thinks it is important that researchers treat people with learning disabilities with respect and give them opportunity to be involved in the research process. Aileen does not want to take part in research where she has no say.

For about six months we met every Wednesday to work on the project. Some of those meetings took only a few minutes and other meetings lasted longer or up to 2 h. Some were practical meetings where we organized things like trips to conferences and applied for travel grants. In other meetings we discussed Aileen's life, recorded the conversations on tape and Kristín made transcripts. Aileen received copies of these transcripts. Aileen decided on the topics of conversations but Kristín asked open ended questions and used 'gentle probes' when required.

Also, Aileen wanted us to talk to family members about her life and she made decisions about which events or social activities Kristín should participate in with her. We have done some analysis together; mostly through discussions. Kristín's role is then to place Aileen's story with the other stories into historical and theoretical context.

The writing process

Walmsley & Johnson (2003) point out that when nondisabled researchers co-author work with people with learning disabilities it is considered good practice to describe the writing process. Following their advice, this paper is based on discussions and reflections on our collaboration where we explored strengths and weaknesses of our partnership. We spent considerable time preparing this paper and recorded our meetings on tape. Then separately we wrote down our reflections and finally Kristín incorporated all of these into this paper and put our thoughts in to context with other writings on the subject of inclusive research. In this paper we want to represent a joint voice, which is a product of our collaboration. Aileen has dual nationality, Icelandic and British. She reads, writes and speaks fluent English, which made it possible for her to take part in all stages of the writing of this paper.

Inclusive research

When reflecting on our work we realized that in some ways our collaboration has limitations and raised the question if it is in fact truly inclusive research. Walmsley & Johnson (2003) have offered criteria for inclusive research with people with learning disabilities based on five principles. We use that criteria as a framework for our reflections and compare our collaboration to these five principles.

First, the research problem should be owned by disabled people, but can be initiated by nondisabled researchers (Walmsley & Johnson 2003: 64). The initial idea for the project derived from Kristín's past research and she recruited people with learning disabilities to participate. The research, however, has been shaped by the collaborators and influenced by their interests. The project is based on life histories of six individuals and no one else can own these stories. Still, the final product of the research is Kristín's doctoral dissertation that will be formally owned by her and, to some extent, her supervisor at the university.

Second, the research should further the interests of people with learning disabilities and nondisabled researchers should be their allies (Walmsley & Johnson 2003: 64). Kristín does identify herself as an advocate for disabled people. Both personal and professional reasons motivated her to take on this project. Shakespeare (2006: 196) has pointed out that nondisabled people also have a stake in disability and many nondisabled researchers are 'first

degree relatives of disabled people'. That would include Kristín whose older brother had learning disability. On the other hand postgraduate students are probably the least powerful individuals in the research community (Paechter 1996) and the doctoral dissertation will most likely receive little attention from policy makers and professionals. It should not be surprising that Aileen does not view the doctoral dissertation as the final product of this project. Her expectations go beyond the limitations of the doctoral project and she has already started to prepare further publications of our research collaboration.

Third, the research should involve people with learning disabilities in the research process (Walmsley & Johnson 2003: 64). All of the collaborators were invited to participate in the research process, including analysis and writing papers. Although all of them wanted to share their stories, only Aileen and one of the young men were interested in getting involved in the whole research process. Three of them did not have time to become involved and one was not interested in writing papers or going to conferences.

Fourth, people with learning disabilities should have some control over the research process and outcomes (Walmsley & Johnson 2003: 64). All the collaborators decided on the topics of our conversations. They also made decisions about which social activities Kristín would participate in with them and whether Kristín should interview other people (usually friends and family) about their lives. However, since this is a doctoral project we must follow the doctoral guidelines of the university and these guidelines restrict our collaboration. For example, Aileen and the other collaborators will not be co-authors of the dissertation and traditionally only pseudonyms are used in the text. However, Aileen's position is slightly different since this paper will be a part of the doctoral dissertation. As a result she co-authors that particular section of the dissertation. The collaborators in the study will have an opportunity to respond to what is written about them in the dissertation and will have the final say in how their story is presented.

Finally, research questions, the research process and reports should be accessible to people with learning disabilities (Walmsley & Johnson 2003: 64). Again, although most of the research process is accessible to people with learning disabilities, the project is limited in its inclusiveness because of doctoral guidelines and language. The theoretical framework of the study was chosen in collaboration with Rannveig Traustadóttir who is Kristín's supervisor and the collaborators were not included in that decision. The dissertation will be written in English and only two of the six collaborators are able to read English. Furthermore, it will be written in language that is acceptable to the research community. This language and the use of theory and terminology will not be accessible to most of the collaborators. There are, however, other possibilities of publishing the research findings in forums and formats that

are more accessible to people with learning disabilities, for example in plain Icelandic and English.

We have compared our collaboration with the five criteria of inclusive research set forth by Walmsley & Johnson (2003) and have come to the conclusion that doctoral projects such as this one can most likely never be fully inclusive. However, we also fear that if the five criteria described above are viewed too literally they could exclude some people from participation in research. For many different reasons not everyone is interested in becoming actively involved in the research process and if we aim for inclusion we will need to make adjustments and look at active involvement as optional.

Collaborative life histories

If you want to know me, then you must know my story,
for my story defines who I am (McAdams 1993: 11).

Life history research has been used successfully in research with people with learning disabilities; it enables them to recall the past, bring structure to their lives and view themselves in historical context (Angrosino 1994; Booth & Booth 1994; Goodley 2000). The life history approach with people with learning disabilities is relatively new in Iceland. Recently, however, a growing number of collaborative life histories have been published in Iceland (Hreinsdóttir & Stefánsdóttir 2004; Sigurjónsdóttir & Traustadóttir 2001; Stefánsdóttir 2003, 2004, 2006; Stefánsdóttir & Traustadóttir 2006) but these only involve a handful of people.

In newly published life histories of three Icelandic women with learning disabilities, the women state that one reason for telling their stories about how they were treated in institutions is to prevent the situation happening again to other people (Stefánsdóttir 2006). Similarly, Aileen has a strong conviction about telling her story. She believes that her story can have an influence on those who write about disabled people, those who work with disabled people and disabled people themselves. Aileen is a young woman and does not belong to the generation of people who were commonly institutionalized. Yet, her life has been eventful and she thinks her story could help others. There are many accounts of social exclusion and oppression in her life but her story is also filled with accomplishments and achievements. Through our collaboration we have realized the importance for her as a self-advocate to share her experiences with others through research. Aileen's life has for the past six years been very much focused around her self-advocacy group and it is also interesting how her role as a co-researcher and self-advocate are interwoven and driven by the need to be heard (Goodley 2000).

Self-advocacy groups are very important in making ourselves heard. When I joined Átak I knew that it was

a place to discuss our issues. If we do not voice our opinions in public we will never get the same rights as other people. I think that it has been a valuable experience to join this group and take part as an active self-advocate. It has also given us the courage to speak up at conferences, meetings and other venues (From Aileen's research notes).

Taking part in this research is only one way in which Aileen tells her story. She has spoken about her life in Iceland and at international conferences. She has told her story on TV and in newspapers. She feels strongly about people with learning disabilities telling their stories and believes that they should not leave it up to their families and professionals to speak up and fight for equal rights. Inclusive research and life history research is by many believed to be empowering for the participants (Angrosino 1994; Atkinson 2004; Stefánsdóttir & Traustadóttir 2006; Walmsley & Johnson 2003). It would be an oversimplification of Aileen's life to say that her involvement in this research is what has empowered her. It is rather a combination of many impressive things in her life including successful employment, independent living and the participation in the self-advocacy group. Goodley (1999, 2000) points out that we need to be careful not to attribute people's empowerment solely to the involvement in research because we risk stereotyping them as passive research subjects. He suggests that people with learning disabilities are often 'self-empowered' and accomplished prior to the research. That does not mean we reject the idea of empowerment through research and we agree that the collaboration has been enjoyable and empowering for both of us.

Empowerment is not necessarily limited to the lives of the research collaborators. Atkinson (2004: 699) points out that life history research can also contribute to empowering practice. Life history research can, for example, influence research practice 'by encouraging participatory research and the reflective researcher'. Life history research is time consuming and we have spent a great deal of time together, which has brought us closer and changed the power relationship between us. At the beginning of our collaboration Aileen was the participant and Kristín was the researcher. Kristín's prior work has mainly been ethnographic and she did not have any formal training or experience in inclusive research prior to this project. After spending much time talking about Aileen's life and in many instances about Kristín's life, writing papers together, travelling and socializing we have become colleagues and adopted defined social roles as the doctoral student and the co-researcher. Collaborating on this research project and using a life history approach has shown us how much we have in common and the differences cease to preoccupy our work (Bogdan & Taylor 1994).

Aileen's story and our collaboration has been a great influence on me as a researcher. Her involvement in the research process has forced me to be reflexive and to find ways to include her in different research activities. Her life history has had much impact on my own life history. I admire her for telling her story and I am grateful to her for trusting me with it and allowing me to use it as a part of my doctoral project. There are always risks involved with collaboration like this. She is taking a big risk by telling her story. I hope I will have the courage to tell my story one day (From Kristín's research notes).

Life history research with people with learning disabilities has been criticised for focusing too much on difficulties and oppression, instead of their resistance and resilience, and therefore fostering negative stereotypes of tragic lives (Atkinson & Walmsley 1999; Stefánsdóttir 2006). We do not claim that our collaboration and experience is representative of all inclusive or collaborative life history research. Nor do we suggest that Aileen is the typical self-advocate because she is in fact a high-profile advocate who has become known locally and nationally. She believes that it is her duty not only to speak up for herself but also to be a voice for other people who can not express themselves. Shakespeare (2006) argues that even though someone is disabled it does not mean that they can automatically report on what other disabled people are experiencing. And self-advocates have in the past claimed that they have not been allowed to tell their story or speak up because they are considered too able or not typical of people with learning disabilities (Goodley 2000). However, we believe that these reflections may in some way contribute to the knowledge of lived experiences of people with learning disabilities and their participation in collaborative life history research. We hope that by adding one story at a time to the growing body of inclusive learning disability research we are contributing to the collective story of people labelled with learning disabilities.

The social field of disability studies

We presented some of our reflections on our research collaboration in a recent Disability Studies Conference in the UK. After attending a few sessions Kristín became anxious that our work was not theoretical enough for this venue. Aileen on the other hand had few worries and said that people would be relieved to hear something accessible especially since our presentation was late in the day. The presentation was a success and when embarking on writing this paper we had not considered applying social theory to our reflections. It was however suggested to us that we should connect this paper to the theoretical framework of the study. It was then Kristín's role to do so and in such a manner that it would be accessible for Aileen to comment on.

Above we state that our collaboration has limitations and blame much of it on doctoral guidelines and academia. And we also regard ourselves as two researchers who have little power in the social field of disability studies. To clarify this we will draw on and adapt Bourdieu's theory on cultural capital. In social fields people compete for positions and power by using capital. Different people have unequal access to capital and are in uneven positions to acquire it (Bourdieu 1984, 1991). Bourdieu (1984) describes four main types of capital: economic, social, cultural and symbolic capital. For the purpose of this paper we will focus on cultural capital. Cultural capital is a form of value associated with knowledge, skills and taste. For example, in the field of education an academic degree would be considered cultural capital (Bourdieu 1978, 1984; Webb *et al.* 2004). The field of disability studies is, in part, defined by the shared rejection of medical views on impairment and disability and is 'intermediate' to the fields of disability and academia. The field of disability studies, like all other fields, is a site of struggle and is structured in terms of power relations (Bourdieu 1977; Jóhannesson 1993, 2006). According to Bourdieu's theory of cultural capital certain forms of knowledge are more highly valued and those who possess this knowledge are therefore more connected to mainstream social institutions. These individuals have greater opportunities to assert their linguistic and cultural competencies and shape the *norm*. In other words, those who have the most power in a cultural field are also those who decide what constitutes capital (Bourdieu 1984, 1990).

At the conference mentioned above a key-note speaker argued that preferably only disabled people should conduct disability research. This was something we had heard before (Oliver 1996). This was the first account of our lack of capital at the conference and we felt 'out of place'. Kristín questioned her right to participate as a nondisabled researcher and Aileen felt that this view could limit the opportunity of people with learning disabilities to participate in disability research. Disability studies in the UK are defined in relation to the British social model of disability. Although the social model has its roots in the disabled people's movement it has been criticised for leaving out people with learning disabilities (Chappell 1998; Goodley 2000).

People with learning disabilities do not seem to possess the capital needed to acquire power in the field of disability studies. This is largely due to lack of access and it seems to us that people with learning disabilities are underrepresented in most aspects of the field of disability studies. For example, there are only a few people with learning disabilities who hold research positions and people with learning disabilities are underrepresented at universities, on editorial boards for disability journals and on ethics committees. Furthermore, most publications on learning disabilities are written by nondisabled scholars.

We had only attended a few sessions at the conference when we realized that neither of us had the language skills or knowledge to follow many of the presentations. Docherty *et al.* (2005) claim that people with learning disabilities need accessible language, large print and even pictures to fully participate in the field of academia. Kristín views herself as a creative person and is quite skilled in drawing. She raised the idea of using pictures and multi-media instead of relying on the written and spoken word for the conference presentation. Aileen rejected the idea and feared that our project would not be taken seriously and might even be regarded as childish. Her arguments are in line with the experience of Goodley & Moore (2000) who constructed a conference paper where they used a combination of text and pictures to make their research findings more accessible. They claim that some of the other researchers dismissed the paper because it was not written and presented in the traditional academic manner. Thus, we used scholarly accepted language because we were competing for acceptance and power in the social field of disability studies and were aiming to maximize our profit by following the rules set by the dominant group of people who have not been labelled with learning disabilities (Bourdieu 1991).

It seems evident to us that the contributions of people with learning disabilities are devalued in the 'intermediate' academic field that relies on academic authority, jargon and often complex theories. Also it seems that nondisabled researchers are devalued as well in the field of disability studies where disability is viewed as capital. This raises new questions about our collaboration and we wonder if learning disability research should be excluded altogether from more theoretical approaches and if we should leave the theoretical interpretations on impairment and disability to disabled researchers who have not been labelled with learning disabilities.

My fear is that inclusive researchers are so fearful of saying things which people with learning difficulties cannot follow that they say very little, leaving the field of theorising to others, including disabled scholars, with little or no commitment to inclusion (Walmsley 2001: 202).

Bourdieu (2000) argues that individuals in a social field employ strategies to increase their capital and positions within the field. Our strategy is inclusive research, writing collaboration and participation in disability studies conferences. In a social field one can transfer one kind of power into another and ultimately into economic advantage and symbolic capital, i.e. authority and prestige (Bourdieu 1988; Jóhannesson 2006). If Kristín successfully completes her degree she should be in a good position to obtain capital in the field of academia and by collaborating with Aileen she increases her capital within the 'intermediate' field of disability studies. Aileen, on the other hand, is faced with

lack of access to both of these fields. It is interesting that we claim that disability research should combat social exclusion. Similar Boudieu argues that education should distribute cultural competencies and cultural capital to work against social exclusion (Bennett & Savage 2004). It seems to us that because of limited educational opportunities and limited opportunities to get involved in research people with learning disabilities are once again faced with social exclusion. However, by writing this paper we are 'gambling' for capital in order to improve our position within the field of disability studies. We are hoping to gain recognition and respect so that we can obtain the capital needed to transform our own value and place within the field (Bourdieu 2000; Webb *et al.* 2004). In the end we can perhaps contribute to the transformation of the field itself.

Conclusion

This paper has reflected on research collaboration between a co-researcher with learning disabilities and a nondisabled doctoral student. It is our claim that doctoral projects can not be fully inclusive largely because of academic expectations and requirements. However, we also argue that it should be possible to make any kind of research inclusive, at least to some extent. Our collaboration has been rewarding and empowering for both of us. We believe it is important for people with learning disabilities to have the opportunity to tell their story and have a say in the research process. They should be able to have some power over what is written about them just as they should have power over their own lives. An article written by learning disabled researchers working in partnership with nondisabled researchers states:

There's a lot of things that are misunderstood or misquoted about learning disability and it's time they included what we've got to say and what other learning disabled people have got to say, not just the professionals' and experts' views (Docherty *et al.* 2005: 31).

Although many nondisabled researchers have established research partnerships with learning disabled researchers, most publications on participatory research with people with learning disabilities are written by nondisabled researchers (Atkinson 2002). It is most likely because of academic expectations and regulations about publication records and among those are the doctoral guidelines we had to follow. We hope our work has contributed in small ways to the inclusive learning disability research literature. We think inclusive research and collaborative writing is no less valuable than other disability research practices and should be taken seriously by policy makers and academia. We encourage researchers to 'invest' in research collaboration because accessibility should not only refer to buildings, education, employment and other social matters. It should

also include research processes, research outputs and the overall field of disability studies otherwise we partake in the exclusion of people with learning disabilities in the same way we criticise society for doing.

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References

- Angrosino M.V. (1994) On the bus with Vonnie Lee. *J Contemp Ethnogr*, **23**: 14–28.
- Atkinson D. (2002) Self-advocacy and research. In: Grey B, Jackson R., editors. *Advocacy & learning disability*. London, Jessica Kingsley Publishers pp 120–136.
- Atkinson D. (2004) Research and empowerment: involving people with learning difficulties in oral and life history research. *Disabil Soc*, **19**: 691–702.
- Atkinson D. & Walmsley J. (1999) Using autobiographical approaches with people with learning difficulties. *Disabil Soc*, **21**: 203–16.
- Barnes C. (2004) Reflections on doing emancipatory disability research. In: Swain J., French S., Barnes C., Thomas C., editors. *Disabling barriers – enabling environments*. 2nd ed. London, Sage publications.
- Bennett T. & Savage M. (2004) Introduction: cultural capital and cultural policy. *Cultural Trends*, **13**: 7–14.
- Bogdan R. & Taylor S.J. (1994) *The social meaning of mental retardation: two life stories*. New York, Teachers College Press.
- Booth T. & Booth W. (1994) The use of depth interviewing with vulnerable subjects: lessons from a research study of parents with learning difficulties. *Soc Sci Med*, **39**: 415.
- Bourdieu P. (1977) *Outline of a theory of practice*. Cambridge, Cambridge University Press.
- Bourdieu P. (1978) Sport and social class. *Soc Sci Inf*, **17**: 819–40.
- Bourdieu P. (1984) *Distinction: a social critique of the judgement of taste*. Cambridge, University Press.
- Bourdieu P. (1988) *Homo academicus*. Stanford, Stanford University Press.
- Bourdieu P. (1990) *In other words: essay towards a reflexive sociology*. Stanford, Stanford University Press.
- Bourdieu P. (1991) *Language & symbolic power*. Cambridge, Harvard University Press.
- Bourdieu P. (2000) *Pascalian meditations*. Cambridge, Polity Press.
- Boxall K. (2007) *Kathy talks about writing in partnership*. Available online: http://partnership.education.manchester.ac.uk/documents/kathy_talks_full.htm
- Boxall K., Carson I. & Docherty D. (2004) Room at the academy? People with learning difficulties and higher education. *Disabil Soc*, **19**: 99–112.
- Carson I. & Docherty D. (2002) Friendships, relationships and issues of sexuality. In: Race D.G., editor. *Learning disability: a social approach*. London, Routledge.
- Chapman R. & McNulty N. (2004) Building bridges? The role of research support in self-advocacy. *BJLD*, **32**: 77–85.
- Chappell A.L. (1998) Still out in the cold, people with learning difficulties and the social model of disability. In: Shakespeare T., editor. *The disability reader*. London, Cassell.
- Chappell A.L. (2000) Emergence of participatory methodology in learning difficulty research: understanding the context. *BJLD*, **28**: 38–43.
- Docherty D., Hughes R., Phillips P., Corbett D., Regan B. et al. (2005) This is what we think. In: Goodley D., Van Hove G., editors. *Another disability studies reader: people with learning disabilities & a disabling world*. Antwerpen, Garant Uitgevers.
- ESRC seminar series (2007) *Service user agendas in research: emancipatory and inclusive paradigms. How can we work together as researchers?* Available online at: <http://www.open.ac.uk/hsc/ESRCseminars/>
- Goodley D. (1999) Disability research and the “Researcher template”: reflections on grounded subjectivity in ethnographic research. *Qualitative Inquiry*, **5**: 24–46.
- Goodley D. (2000) *Self-advocacy in the lives of people with learning disabilities*. Buckingham, Open University Press.
- Goodley D. & Moore M. (2000) Doing disability research: activist lives and the academy. *Disabil Soc*, **15**: 861–82.
- Ham M., Jones N., Mansell L., Northway R., Price L. et al. (2004) ‘I’m a researcher!’ Working together to gain ethical approval for a participatory research study. *J Learn Disabil*, **8**: 397–407.
- Hreinsdóttir E. & Stefánsdóttir G. (2004) Ráðstefna í Englandi: saga sjálfsákvörðunarhópa [Conference on the history of self-advocacy, life history and inclusive research with people with intellectual disabilities, not available in English]. *Þroskahjálp*, **2**: 23–9.
- Hreinsdóttir E., Stefánsdóttir G.V., Lewthwaite A., Ledger S. & Shufflebotham L. (2006) Is my story so different from yours? Comparing life stories, experiences institutionalization and self-advocacy in England and Iceland *BJLD*, **34**: 157–66.
- Jóhannesson I.Á. (1993) Professionalization of progress and expertise among teacher educators in Iceland: a Bourdieuan interpretation. *Teacher & Teacher Education*, **9**: 269–81.
- Jóhannesson I.Á. (2006) Concept of teacher knowledge as social strategies. *Pedagogy, Culture & Society*, **14**: 19–34.
- Johnson K. & Traustadóttir R., editors (2005) *Deinstitutionalization and people with intellectual disabilities: in and out of institutions*. London, Jessica Kingsley Publishers.
- Klotz J. (2004) Sociocultural study of intellectual disability: moving beyond labelling and social constructionist perspectives. *BJLD*, **32**: 49–109.
- McAdams D.P. (1993) *The stories we live by: personal myths and the making of the self*. New York, Guilford Press.
- Mitchell D., Traustadóttir R., Chapman R., Townson L. & Ingham N., editors (2006) *Exploring experiences of advocacy by people with learning disabilities: testimonies of resistance*. London, Jessica Kingsley Publishers.
- Oliver M. (1996) *Understanding disability: from theory to practice*. New York, Martin’s Press Scholarly and Reference Division.

- Paechter C. (1996) Power, knowledge and the confessional in qualitative research. *Discourse: Studies in Cultural Politics of Education*, 17: 75–84.
- Park P., Brydon-Miller M., Hall B. & Jackson T., editors (1993) *Voices of change: participatory research in the United States and Canada*. Westport, Begin & Garvey.
- Ramcharan P., Roberts G., Grant G. & Borland J., editors (1997) *Empowerment in everyday life: learning disability*. London, Jessica Kingsley Publishers.
- Roets G., Van de Perre D., Van Hove G., Schoeters L. & De Schauwer E. (2004) An account of the joint fight for human rights by Flemish Musketeers and their Tinker Ladies. *BJLD*, 32: 54–64.
- Shakespeare T. (2006) *Disability rights and wrongs*. London, Routledge.
- Sigurjónsdóttir H.B. (2004) Intellectually limited fathers, their families and formal support services. In: Kristiansen K., Traustadóttir R., editors. *Gender and disability research in the Nordic countries*. Lund, Studentlitterature.
- Sigurjónsdóttir H.B. & Traustadóttir R. (2001) *Ósýnilegar fjölskyldur: Seinfærar/Þroskaheftar mæður og börn þeirra [Invisible families: Mothers with learning difficulties and their children, not available in English]*. Reykjavík, University of Iceland Press.
- Stefánsdóttir G. (2003) Lífssaga Ragnheiðar Guðmundsdóttur [The life story of Ragnheiður Guðmundsdóttir]. In: Traustadóttir R., editor. *Fötlunarfræði [Disability Studies: new Icelandic research, not available in English]*. Reykjavík, University of Iceland Press.
- Stefánsdóttir G. (2004) Birtingamyndir andófs og mótspyrnu í lífssögum þriggja kvenna með þroskahömlun [Resistance and resiliants in the life histories of three women with intellectual disabilities]. In: Hauksson U., editor. *Rannsóknir í félagsvísindum V [Research in social sciences V: Faculty of social sciences, not available in English]*. Reykjavík, University of Iceland Press.
- Stefánsdóttir G. (2006) 'Ég hef svo mikið að segja'. Um ævisögulegar lífssögurannsóknir [“I have so much to say”: on biographical life history research]. In: Traustadóttir R., editor. *Fötlun: Hugmyndir og aðferðir á nýju fræðasviði [Disability: Ideas and methods in a new field of study, not available in English]*. Reykjavík, University of Iceland Press.
- Stefánsdóttir G. & Traustadóttir R. (2006) Resilience and resistance in the life histories of three women with learning difficulties in Iceland. In: Mitchell D., Traustadóttir R., Chapman R., Townson L., Ingham N., editors. *Exploring experiences of advocacy by people with learning disabilities: testimonies of resistance*. London, Jessica Kingsley Publishers.
- Traustadóttir R. (2006) Fötlunarrannsóknir: Áherslur og álitamál í rannsóknnum með fötluðu fólki [Disability research: New emphasis and challenges in researching with disabled people]. In: Traustadóttir R., editor. *Fötlun: Hugmyndir og aðferðir á nýju fræðasviði [Disability: Ideas and methods in a new field of study, not available in English]*. Reykjavík, University of Iceland Press.
- Walmsley J. (2001) Normalisation, emancipatory research and inclusive research in learning disability. *Disabil Soc*, 16: 187–205.
- Walmsley J. (2002) Principles and types of advocacy. In: Gray B., Jackson R., editors. *Advocacy & learning disability*. London, Jessica Kingsley Publishers.
- Walmsley J. & Johnson K. (2003) *Inclusive research with people with learning disabilities: past, present and futures*. London, Jessica Kingsley Publishers.
- Webb J., Schirato T. & Danaher G. (2004) *Understanding Bourdieu*. London, Sage Publications Ltd.