Purpose, Process and Future Direction of Disability Research

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Purpose, Process and Future Direction of Disability Research brings together the collective experience of an international network of early career researchers who set out to discuss the complexity of researching disability. As newcomers to the research process, the researchers detail their apprehensions about embarking on doctoral research, together with the struggles they experienced along the way, and importantly the motivation that drove them to complete their projects.

Contributors present an open and honest reflection on their research experience. Interests, motives and values which underpinned the direction of their research projects are explored, questioning whether their beliefs were subsequently challenged, changed or validated. Research decisions were driven by a range and combination of personal experience of disability and professional experience of working with disabled people. The influence of personal and professional approaches within research is addressed, along with subsequent dilemmas. Ideological battles are detailed, which include: the place of the social model of disability in research; and the oppressive nature of doing disability research. The researchers identify and examine their experience throughout the process of analysis, writing-up and presenting data and question how far their data resulted in confusions or conclusions. Contributors explore their moral and political position as researchers, and the potential influence on the validity of their findings. Issues about dissemination and the impact of their findings are also considered. Future research aims and challenges are identified with each contributor critically questioning the unfinished business that their research has involved.

Essential reading recommended for students and supervisors engaged in disability studies and inclusive education.
Purpose, Process and Future Direction of Disability Research
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Scope
This series addresses the many different forms of exclusion that occur in schooling across a range of international contexts and considers strategies for increasing the inclusion and success of all students. In many school jurisdictions the most reliable predictors of educational failure include poverty, Aboriginality and disability. Traditionally schools have not been pressed to deal with exclusion and failure. Failing students were blamed for their lack of attainment and were either placed in segregated educational settings or encouraged to leave and enter the unskilled labour market. The crisis in the labor market and the call by parents for the inclusion of their children in their neighborhood school has made visible the failure of schools to include all children.

Drawing from a range of researchers and educators from around the world, Studies in Inclusive Education will demonstrate the ways in which schools contribute to the failure of different student identities on the basis of gender, race, language, sexuality, disability, socio-economic status and geographic isolation. This series differs from existing work in inclusive education by expanding the focus from a narrow consideration of what has been traditionally referred to as special educational needs to understand school failure and exclusion in all its forms. Moreover, the series will consider exclusion and inclusion across all sectors of education: early years, elementary and secondary schooling, and higher education.
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LIST OF CONTRIBUTORS

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Marion Reichart is a lecturer in Law and the Social Sciences at the Open University, a member of Lawyers with Disabilities Division Law Society, and an Associate of the British Institute of Human Rights (BIHR). Shaped by personal and professional experience of disability, Marion seeks to promote respectful inclusion, anti-discrimination and human rights approaches to grass-root, business, government and public sector clients. She has disseminated best practice strategies for the former Disability Rights Commission, given keynotes on the UN Convention on the human rights of disabled people, and presented at Disability Intergroup, European Parliament in Brussels. Originally Marion qualified as an ergotherapist in 1982 in Heidelberg (Germany). She holds a First Class Honours Degree in Law (Thames Valley University, London) and in 2007 completed her PhD Connecting disability equality and citizenship education at the University of Greenwich, UK.

Ilektra Spandagou is a senior lecturer at the Faculty of Education and Social Work, University of Sydney, Australia. She has been involved in teacher education in special and inclusive education both in Greece and Australia. She has experience of working with general and special education teachers in the area of theories of inclusive education, and the nexus of policy and school practice. Ilektra’s research interests include inclusion, disability, comparative education and classroom diversity. Her publications include the recently published book Inclusive education: International policy & practice (co-authored with A. C. Armstrong and D. Armstrong).

Simoni Symeonidou is a lecturer in Inclusive Education at the Department of Education of the University of Cyprus. She holds degrees from the University of Cyprus (BEd in Primary Education), the University of Manchester (MEd in Special Needs and Development) and the University of Cambridge (PhD in Education). Her research interests include the history, policy and practice of inclusive education in Cyprus and in other countries, inclusive education curriculum and pedagogy, teacher education for inclusion, disability studies and disability studies in education. She is actively involved in networks and associations which promote inclusive education issues and she has published widely in international journals. Her publications include a book in Greek entitled Teacher education for inclusion: From research to praxis (co-authored with H. Phtiaka). Simoni is the scientific co-ordinator of the website Tessearae of Knowledge (www.ucy.ac.cy/psifides-gnosis).
This is an important, original set of papers addressing a selection of significant issues, conceptions, policies, intentions and experiences, relating to cross-cultural research approaches to disability studies and inclusion.

Editing a collection of papers is a challenging, complex and time-consuming task. Deciding on the themes of the book, providing significant, critical, constructive feedback to the authors, is an essential responsibility of such editorial work. Keeping authors involved in the project, getting deadlines met, making decisions relating to the order of the papers, are also examples of their tasks. Good editing can enhance the overall quality of a book.

This is the first time these two colleagues have worked together as editors of a book. They have taken on their responsibilities in an enthusiastic and serious manner. Each paper has benefitted from their perceptive, detailed comments and support. The overall quality of the book is partly a reflection of the painstaking efforts of their work.

The contributors have provided a refreshingly open, honest, self-critical approach covering a range of features relating to their doctoral research experiences. Their accounts evidence a serious, passionate, sustained commitment to the struggles involved in attempting to increase their knowledge and understanding of what it means to be a researcher in a specific context, investigating chosen topics. Research is viewed as a complex learning process, which involves exciting, developmental aspects of engagements and outcomes as well as those elements of uncertainty, doubt and frustration. Hence, there is an element of messiness to this whole process.

In various ways, the contributors view research practice as a continual process of learning and re-learning. Taken-for-granted assumptions, conceptions and practices, are increasingly subject to critical examination. Change is foregrounded in the pursuit of providing more enabling, liberating, research intentions, relations and outcomes.

Overall, a range of important factors are identified and discussed in relation to the complex challenges that the authors encountered throughout their research endeavours, including: establishing an acceptable focus of the research; constructing the research questions; choosing and engaging with specific methods and methodological concerns; developing an heightened awareness of issues relating to the positionality of the researcher; working through the complex and contentious issues relating to conceptual clarity and theoretical frameworks; social model thinking and its implications for research; learning to think, read and write critically; making sense of the findings; various ethical concerns; relationships with participants and the position and role of the supervisor. The overall impact of these carefully focused and analysed accounts, vividly confirms the quality and degree of the time, emotional and intellectual labour that has been involved on the part of the authors.
FOREWORD

This collection of papers provides a rich source of perceptive, thoughtful, thought-provoking ideas, insights, challenging questions and relevant literature. The editors hope that this volume will inspire and encourage readers to pursue high quality research. I welcome the publication of this volume and believe it should be widely read and seriously discussed, especially by students and supervisors engaged in inclusive education and disability studies, for whom it should be essential reading.

Professor Emeritus Len Barton
Institute of Education
University of London
ACKNOWLEDGEMENTS

We are indebted to those who provided valuable guidance and support (whether as a supervisor, mentor or friend) in our early steps of researching disability. As detailed in our chapters we are appreciative of those academics, researchers and activists who introduced groundbreaking debates about doing disability research, which impacted on our way of thinking about our own research.

The idea of forming a network of early career researchers resulted from the encouragement of Professor Len Barton, and enabled a sharing of views about our experiences of the research process. It was at the suggestion of Len that we decided to develop these ideas and to put together a collection of our papers. We are grateful to Len for his advice and support, and his ongoing encouragement and commitment to our work.

We would like to thank Professor Roger Slee and his editorial board for including our volume as part of the series *Studies in Inclusive Education*. 
1. INTRODUCTION

The content of this volume stems from the experiences of a network of early career researchers with an interest in researching disability. Each of us had recently completed doctoral research and following the encouragement of Professor Len Barton, we formed an international network to share our experiences about researching disability and to contemplate on the purpose, process and future direction of disability research.

Following the initial exchange of details about our doctoral studies it was evident that whilst our approaches differed and our experiences were varied in researching disability across countries and contexts, we were unified by an underpinning desire to explore ideas about researching disability. We were further unified by being a network of female researchers, although the significance of gender on our research varied. As a network of newly qualified researchers we had much to offer, and to say, about our experiences of researching disability.

We present an open and honest reflection on our experiences as postgraduate students, with each of us considering the factors that influenced the direction of our research and the decisions we reached. We sought to identify our interests, motives and values which underpinned our work and to question whether our beliefs were subsequently substantiated, validated, challenged or changed. Our decisions were driven by a range and combination of personal experience of impairment and disability, and professional experience of working with disabled people. The influence of personal and professional approaches within our research is addressed, along with the dilemmas that this might have caused. As newcomers to the research process we discuss our apprehensions about embarking on doctoral research, together with the anxieties experienced along the way, and importantly the motivation that drove us to complete our projects.

Whilst our research focus varied, the purpose of our research was united in furthering debate and understanding about power relationships and the inequality and marginalization experienced by disabled people. Discussion reflects on barriers of power within politics, policy and practice, and the struggle by disabled people in challenging their exclusion. Therefore, many of the chapters discuss the lack of voice experienced by disabled people and the research purpose being one of enabling unheard voices to be heard in the struggle to inform legislation, policy and practice.

We reflect on theoretical discussions within disability studies and inclusive education research and examine the way in which debates about the meaning of
disability and inclusion determined or influenced the direction of our work. Of particular significance is our understanding of disability in terms of the medical and social model (Oliver, 1990; 2009; Oliver & Barnes, 2012): the medical model reflecting impairment as individual limitation; the social model identifying disability as socially produced dependency. We explore the influence of discussions about the relationship between individual and societal factors and their impact on our research approach, design and analysis of findings. Moreover, where initial research positions were challenged or changed during the research process, the impact of a different approach or direction on the project is addressed.

The influence of discussions within disability studies about the purpose and process of doing disability research on our work is considered. In particular, the powerful contributions featured in the special edition of *Disability, Handicap and Society* in 1992, which identified the frustration and disillusionment surrounding disability research by researchers and researched. As Barton stated:

> Criticisms of such research included their misunderstanding of the nature of disability, their distortion of the experience of disability, their failure to involve disabled people and the lack of any real improvements in the quality of life of disabled people that they have produced. (1992, p. 99)

The groundbreaking articles, within the special edition of the journal, highlighted the importance of developing effective and meaningful research strategies. An edited volume *Doing disability research* (Barnes & Mercer, 1997) continued to challenge traditional and dominant approaches to researching disability and addressed the importance of adopting an ‘emancipatory’ research process. For those of us with a specific research interest in inclusive education other valuable texts included: *Making difficulties: Research and the construction of SEN* (Clough & Barton, 1995); and *Doing inclusive education research* (Allan & Slee, 2005).

The principles underpinning our work varied and we each address ways in which we were persuaded in the decisions taken about our methodological choices. Discussion reflects on those decisions and the appropriateness of approach, along with any regrets over a particular direction taken. The different approaches provide the opportunity of exploring a wide range of research methods (for example the use of observation and in-depth interviewing), together with supporting strategies (for example in-depth case studies and documentary analysis) aimed at strengthening and validating our research.

We identify and examine some of our experiences throughout the process of analysis, writing-up and presenting data and question how far the data resulted in confusions or conclusions. Moreover, we explore our moral and political position as researchers, and the potential ways it might have influenced the validity of findings. Issues about dissemination and the impact of our findings are also considered. Significantly, we question whether our findings influenced policymakers, professionals, organizations representing disabled people, and disabled people themselves; and whether our research contributed to the empowerment of disabled
INTRODUCTION

people. Developing these ideas we share our thoughts and dilemmas about our future research aims and challenges.

At the end of each chapter each contributor was asked to identify two questions which reflect the unfinished business that their research has involved. We acknowledge that there are relevant topics that remained untouched or topics that were not researched at the level each one of us would have liked to have researched them. By identifying these questions we hope that we will encourage critical discussion by the readers.

As editors, we recognized the value of openly sharing our experiences as novice researchers with others (whether established researchers or those starting out in disability research). Throughout the process of putting together the chapters we encouraged contributors to move away from 'just' providing an account of their research and findings, to questioning and reflecting on those principles which guided their research, with the ultimate aim of developing ideas about the purpose, process and future direction of disability research. The process of revisiting research decisions is challenging and yet at the same time enlightening and thought provoking. Our aim was to encourage authors to provide a self-critical approach, reflecting on their ideology and contribution to the field. The resulting chapters are varied and consequently focus on the importance each researcher attached to the issues outlined.

In Chapter 2, Marion Reichart presents a thought provoking account as she reflects on important influences throughout her research. Her study was about challenging traditional models of citizenship in professional practice and her aim was to connect disability equality to citizenship equality. Marion has a background of law and human rights in Germany and she critically questioned the role of law and the state, together with social and institutional practice, in enabling and dis-abling individuals. She explains how her understanding of the interrelating of the ‘personal’ and the ‘political’ experiences of disabled people deepened during the research and influenced her thought processes. She explores her ideological position and the importance of the social model, human rights and political struggle in her work. She describes the stages which influenced her research decisions and in particular the influences which led her to reach her research questions. From the outset Marion identified the importance of engaging with disabled people in her project and she describes the process of developing a ‘mash-up’ methodology, which would enable her to reach out to a range of authentic disabled voices (from disabled academics to ‘ordinary’ disabled people): an approach which often resulted in conflicting and contradictory viewpoints. However, as Marion discusses, her hope was to provide evidence of the inequality experienced by disabled people. During the latter stages of writing-up Marion writes that her insight deepened into ‘a way of knowing’.

In Chapter 3, Carmel Kelly provides an open and sincere discussion about her research, which explored disability discourses and disciplinary practices in a local authority care management team in England. Carmel sought to identify whether discursive shifts towards a social model position in political, policy and academic discourses were reflected in everyday practitioner perspectives. She reflects on why
she chose this particular project and the important influence of her previous work experience and personal background, along with her ideological position and her interests in sociology, social policy and social work. She reveals an enthusiasm, as well as an apprehension, about embarking on the project. Carmel provides an account of the reasoning behind her research methodology and methods (observation, semi-structured interviews and documentary analysis) and reflects on the appropriateness and benefits of her chosen approach: an approach which deepened her understanding of the multilayered character of care management practices. A range of research problems and ethical dilemmas are shared, and Carmel’s frankness offers an insight into the quandaries she encountered: for example, her decision to partial nondisclosure of her own social modelist thinking in order to avoid distancing herself from research participants. Throughout the chapter the complexity of power relationships is evident and her discussion is enlightening in drawing out the issues of researching those who are perceived as being in a position of power. The process of unraveling the ‘messiness’ of data discussed is insightful, and Carmel’s concern about the interpretation and validity of her findings is evident. Ultimately, Carmel’s findings identify dominant practitioner views of ‘expert’ status towards disabled people continue to exist, but hidden by social model and user-centered discourses.

In Chapter 4, Simoni Symeonidou identifies the social model as a ‘driving force’ in her research journey. Growing up in Cyprus she reflects on the dominance of the medical and charitable focus towards disabled people and how her understanding of disability was later challenged. Simoni trained as a primary school teacher and since has been interested in inclusive education and disability studies research. At the start of her doctoral study she set out to combine both fields within her work. Her research aim was to contribute to the understanding of disability and the disability movement in Greek-Cypriot culture. As her discussion develops she insightfully details the dilemmas the social model brought into her research: for instance in deciding an appropriate research framework and paradigm. Whilst the social model shaped her research interest, she engaged with feminist (personal experience of impairment and disability, and the personal is political maxim) and postmodern/poststructural (culture, history and identity) ideas: an approach which helped her conceptualize the experiences of disabled people and the disability movement in an historical and cultural context. Simoni is clear in her commitment to the social model and reflects on why she decided not to adopt an emancipatory research paradigm. She explores her decision to take a hermeneutical research approach (an approach which enables the researcher to construct meaning through interpreting multiple realities) in an endeavor to provide an account of the experiences of disabled people at both a personal and political level, within the multifaceted cultural and historical context of Cyprus. Simoni identifies a range of concerns during the process of data analysis, writing-up and dissemination and explores her thoughts on completing her research journey.

In Chapter 5, Ilektra Spandagou provides an informative account of the challenges she experienced in completing a comparative and ethnographic study on
In Chapter 6, Eleni Gavrielidou-Tsielepi considers the influence and impact!of the social model throughout her research approach. Reflecting on her first encounter with the social model (whilst studying to become a pre-primary school teacher in Cyprus), she discusses the way her outlook, views and understanding of disability were challenged: challenges which instigated her desire to pursue research. Eleni felt driven ‘to make a difference’ in achieving inclusion for disabled children in education and questioned why despite a legal framework supporting the ‘rights’ of children in Cyprus, an emphasis persisted on supporting the ‘needs’ of disabled children. Her research questioned the gap between official policy and the implementation of policy in everyday practice and she discusses the influence of Gillian Fulcher in determining her research questions. The decisions about her theoretical and methodological framework are reflected upon and she explores her reasoning in the decisions taken. Her approach of adopting different research methods and techniques (bricoleur), included the analysis of documents, observation of policy processes within schools and semi-structured interviewing: as a result her data proved rich and complex. Reflecting on her findings Eleni identifies the power of the medical model in policy enactment. She exemplifies such power in the way the medical model legitimized professional opinion and influenced decision-making processes.

In Chapter 7, Simona D’Alessio discusses her doctoral study as a process in which her views and understanding about disability and inclusive education radically changed. At the start of her project she believed that the Italian policy of integrazione scolastica (school integration) was progressive and inclusive. However, her original assumptions were challenged and as she argues she experienced ‘a major shift in thinking’. She was influenced by writers in the field of disability studies and within inclusive education, together with the work of Antonio Gramsci and Michel Foucault. A new awareness of inequalities of power within education and policymaking settings developed, together with a realization that the process of integration and inclusion were very different. Her research objective changed and she sought to identify barriers to participation by disabled students, which were often disguised as inclusive policy. From an original individual/medical model position her project followed a new direction and she details the significance of adopting a social model
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approach on her decisions about research questions, choice of methods and design, form of analysis, dissemination and impact of findings. Utilizing research findings Simona provides illustrative examples of different approaches from different perspectives. Her powerful account is a battle of contested ideas and assumptions and although Simona discusses her experiences as a ‘struggle’, she concludes that her research journey proved ‘rewarding’.

In Chapter 8, Karen Beauchamp-Pryor reflects on why she felt driven to identify those factors which worked to include or exclude disabled students in Welsh higher education. Drawing on her personal experience of impairment and disability, together with her growing interest in disability policy and politics, she details their influence on her project. Karen explores the underpinning principles which guided her study (principles which included a commitment to: challenging oppression; adopting an emancipatory approach; researching from an ‘inside’ position as a disabled person; shifting the research focus upwards on to those who influence the direction and implementation of policy and practice; and effective dissemination of research findings) and re-examines her research position. She reflects on the benefits of her approach, together with subsequent dilemmas and regrets, and concludes by questioning whether with hindsight she would have done things differently. Throughout her aim was to develop a framework towards securing inclusion for disabled students in higher education and her research decisions were focused on this aspiration.

The final chapter draws together ‘our’ stories, reflecting on the purpose, process and future direction of disability research. Compiling the volume has been a new experience for us as editors, but from the outset we shared an enthusiasm and desire to put together the experiences, reflections and ideas of network members. Throughout the process we have provided support to each other, as well as receiving encouragement from the network: support and encouragement which has driven the work to completion.

REFERENCES

MARION REICHART

2. A LIBERATING RESEARCH AGENDA: ON HEARING VOICES AND DEVELOPING A WAY OF SEEING

In loving memory of my beautiful son Aaron
February 21, 1988 – March 17, 2013

INTRODUCTION

...there was increasing anger, hostility and suspicion among organizations of disabled people that much that passed as ‘disability research’ was nothing more than a ‘rip-off’. (Oliver, 1997, p. 15)

This paper both tells and reflects upon the story of doing disability equality research. My research focus is on the subject of disability equality and not on disabled people as the object of research. Research about disabled people without control by disabled people is referred to as a ‘rip off’ by Michael Oliver in the above quote. In this chapter, I do not provide a full summary of my research, but instead look back at how a particular way of thinking developed and became a tool in disability equality research. In particular, I reflect upon power relations and show connections between personal and political disability issues.

Liberating research starts with an imagination of future possibilities and requires ‘emancipated’ selves. This chapter offers reflexive biographical sketches of this process and details how three tools developed and strengthened so as to hear authentic disability voices over themes of citizenship: the application of a ‘personal – political zoom’; the adoption of social model thinking (Denkmuster); and the development of an innovative ‘mash-up’ methodology.

My research aim was to connect disability equality to citizenship education (in the UK). From the outset I aspired to have a transformative agenda (Barton, 2005; Oliver, 1997) that is relevant to the lived experiences of disabled people (people with impairments or long-term health conditions) like me. I sought to model ways to engage with disabled people and to reach authentic disability voices, in order to provide evidence of the impact and extent of disability inequality.

The research questions did not appear at the start of the project. Initially, I undertook research in Law, comparing German and British employment legislation and the responses of different legal systems to the question of equality. I wanted to know whether disabled women could rely upon the law to protect their employment rights. I had been interviewing leading disabled women and read copious material on Recht und Gesetz, Acts of Parliament, case law decisions, codes of practices,
commentaries and legal analyses. However, disabled women seemed invisible in these texts. This invisibility needed to be addressed and in this process, I deepened my understanding of the relationship between the personal and political.

THE PERSONAL – POLITICAL ZOOM

It puzzled me that disabled women appeared to be doubly discriminated yet had no legal recourse. Equality laws were widely implemented and available on grounds of race, gender, religion or belief, even on sexual orientation and gender reassignment, but not for disabled people. In Germany (Forum Behinderten Juristinnen und Juristen, 1995; Hermes, 1994) and Britain (Barnes, 1991) and at a European level (Hendriks & Degener, 1994), disabled people were using research evidence controlled by disabled people’s organizations and demanded anti-discrimination laws. Additionally, in Germany, campaigners sought a change in the constitution, so that the non-discrimination clause would explicitly promote basic human rights for disabled people and protect against abuses of state power (Heiden, 1996).

With a professional background in law and human rights I began to ask critical questions about the role of the law and how it shaped, constrained, freed or enabled individuals. This section sketches an example of my early learning about how disabled people fair within legal systems. A socio-legal analysis planted the seeds for a way of understanding of how the law works, of how the law expands and contracts in different economic and political times, and therefore, the influence of law in opening or closing opportunities for disabled people. However, it was not until the writing-up phase of my PhD many years later that a deepening insight crystallized into a way of knowing.

Theresia Degener, one of the disabled lawyers I interviewed, invited me to visit after her first son was born. We discussed many experiences where expectations on women as a mother and as a disabled person intersect. I learned how the German welfare system through its laws and with assumptions about ability and risk, tended to dis-able mothers like her. Theresia is a well known human rights lawyer, a co-author of the original background study to the United Nations Convention (2006) on the rights of disabled persons, professor in law and disability studies and is a legal expert and commissioner in the UN Committee. She was born without arms due to the effects of Thalidomide. Together with her partner and close allies, she had to dissuade overzealous professionals from intervention into her private and family life under the guise of welfare concerns for the child.

During my weekend discussions with Theresia, I discovered that such private endeavors were replicated across impairment categories and reflected a collective pattern of struggle for disabled mothers in Germany (Hermes, 1998; 2002; 2004) and elsewhere. Through these collections of narratives, I was learning a way of hearing voices of disabled parents as they echoed citizenship themes of equality and human rights, of dignity and autonomy, and of the right to private and family life. Narratives illustrate dimensions of citizenship where the personal and political, the private and public, are mutually constitutive: they shape and are shaped by each other (figure 2.1).
My understanding of how the personal and political interrelated grew with each encounter and with subsequent reflections upon disabled people’s experiences, and thus the personal – political zoom developed into a core research tool. For my PhD I examined citizenship themes of ‘equality before the law’. I reflected upon discoveries in the ‘personal’ sphere of disabled parents, whose children had been taken into care, and critically analyzed the ‘political’ sphere of the law, where apparently neutral, formal, equal citizenship rights, such as Article 8 of the European Convention on Human Rights (Council of Europe, 1950), collided with the actual experiences of parents classified as having learning difficulties (Case of Kutzner v Germany, 2002). Operating the zoom onto the political aspects showed how the decisions of social welfare and legal professionals ran counter to human rights principles of disabled people. Yet with a personal zoom, parents classified as having learning difficulties were not passive victims, as they challenged the law and dominant social policy. Personal struggles and resistance influenced the political shape of future possibilities, since case law was decided in their favor and at a European level. Disabled parents turned personal issues into collective political action.

Applying a personal – political zoom chimes with the social model of disability (Oliver, 1990; Oliver & Barnes, 2012). As I explored citizenship issues and the curriculum, my thinking was continually challenged by experiences that showed how disabled people in society were not being heard or responded to in any meaningful way. Disabled people were often without basic human rights, and yet there was resistance and struggle. I felt a strong sense of injustice about these situations. It became clear that doing disability equality research meant addressing and redressing injustice. The next section outlines why I decided to examine injustices on the themes of citizenship in the curriculum.

WHY RESEARCH DISABILITY EQUALITY AND CITIZENSHIP CURRICULUM?

The opportunity for this project arose when the University of Greenwich advertised for a PhD studentship, with Michael Oliver (School of Psychology and Social Sciences) as joint supervisor with Christine Lloyd (School of Education and
Training). I give a description in three stages of the tortuous path of my research-student experience that eventually leads me to develop the ‘mash-up’ methodology: supervision process; ideological warfare; and research questions.

**Supervision Process**

As each supervisor headed a different department, I was straddling two academic fields from the outset. I must admit, curriculum structures, attainment targets, programs of study, and developments leading to the new National Curriculum in England, were unfamiliar to me. Driven by a desire to enter this new academic world, to prove to myself and perhaps to please my supervisors, academic peers, or colleagues, an internalized pressure to fill my perceived knowledge-gap grew. An expectation to become part of the ‘expertise’ was dangerous, in terms of research goals with a transformative agenda. At a political level liberating research seeks to redress disability inequality, and at a personal level, the production of knowledge strives to emancipate myself as a disabled person. For years I had immersed myself in curriculum matters, in the very structures and processes that were oppressive, in policy development and education for citizenship debates. The more I did so, the further away I felt I was getting from a liberating disability research agenda, as too much time was spent on institutional or managerial definitions and less and less on the direct experiences of disabled people.

One of the most beneficial aspects of the supervisory process was that as a researcher I must be enabled to think. When I was considering my research question, Michael Oliver probed why I had decided to take this or that direction. He enabled me to reflect upon motivation and feelings, a process which alerted me to any potential compromise or irrelevance. My second supervisor, Mary Stiasny (who was the new head of the School of Education and Training) was invaluable in her guidance on curriculum structures and education policy, and engaged my creativity. In an open and non-judgmental manner she patiently shared my journey of finding a way to hear disability voices.

A good support network of allies was helpful, but so was time to work things out for myself. Both supervisors allowed me (during periods of apparent inactivity) the space to think, to test ideas, engage in dialogue, and the space to heal and recover. Completing my PhD took eight years: expected completion in just three years would have crushed me, as I often needed space to recover my strength from bullish exchanges in oppressive institutional contexts. An illustration of such ‘warfare’ is given in the next section, where frustrated exchanges left me doubting whether I had any grasp on reality.

**Ideological Warfare**

On July 2, 1999, I attended a conference in London entitled ‘Preparation for adult life: Coherent education for personal and social development?’. Much of the
day was concerned with the Secretary of State’s proposals for citizenship within the revised curriculum. With a professional background in law and personal engagement in disability politics the potential for raising disability equality issues in the National Curriculum seemed obvious to me and filled me with great excitement.

I was soon struck by the self-evident authority of education professionals and their unveiled hostility to the idea that the conference topics were in any way relevant to disabled people. Delegates, speakers and workshop leaders, head teachers, Local Education Authority advisers, special educational needs co-ordinators (SENCOs), and initial teacher trainers (ITTs), all explained in one way or another that ‘special educational need’ (SEN) was a ‘specialist’, separate area. The meaning of my words ‘disability equality’ were ‘stolen, transformed and appropriated’ (Eagleton, 1994, p. 187) in a kind of ideological warfare (Allan & Slee, 2008, p. 53). I said ‘disability equality’ but they heard ‘special needs’ or ‘SEN’ and ‘special educational need’. Disability equality, it seemed, had not (yet) entered the classroom. And when it later did, it often masqueraded as new, when it was a mere use of new words for the same old practices, as Slee explained, practices ‘demonstrating a remarkable resilience through linguistic dexterity’ (2001, p. 167). What annoyed me most was that delegates expressed concern that everyone wanted to jump onto the bandwagon of citizenship. I was told: ‘citizenship teaching must achieve clarity, coherence and manageability’. I felt it loud and clear, the message that disabled people and citizenship in the curriculum did not go together. The uniformity of these messages was stifling.

Of course, ‘special educational need’ was not my area of expertise. My teaching and learning experience was not as a teacher in the classroom at school, but as a Law and Social Science lecturer at university and as a freelance trainer on diversity issues and social change. In the school context, I worked with Disability Equality in Education to challenge exclusionary practices. I was neither familiar with the various administrative techniques that allocated resources, nor acquainted with the changing role of SENCOs. I had been active with the Alliance for Inclusive Education (ALLFIE), on hearing experiences of parents and young disabled people about these procedures. At university, I was inexperienced in the ‘mad, sad, bad’ classifications adopted by some colleagues, who offered an overview of special education history to trainee teachers. For me, special education was another way of saying school failure (Barton, 1997) in a historically exclusionary society.

Further ideological battles played out later, when I tested ideas about the history of oppression of disabled people with an international audience of special education professionals (Innovations in Special Educational Needs Support in Regular Education – INSPIRE). The room was full of good intentions, yet low level oppressive rumblings occasionally leaked out. In one of my sessions, as delegates raised the idea that segregated education was akin to apartheid (a particularly sensitive issue, as the discussions took place in the Netherlands), power erupted and closed down any further dialogue.
Research Questions

All of this left me wondering: What was the position of disabled people in society? And who knows? What models of citizenship were there and what did it mean for disabled people? How could my research reduce and change current stifling, oppressive institutionalized patterns and instead lead to effective expression of disability equality in the teaching of citizenship?

Education professionals no longer go about their tasks in tacit acceptance of a diagnostic deficit frame of mind without being challenged. Disability issues entered academic and professional debate in three main domains of research: inclusive education, special education and disability studies. UK law introduced the concept of disability equality: the amended Disability Discrimination Act (DWP, 2005) required public bodies such as schools, colleges and universities, to consult with disabled people, involve them in planning for services and to publish action plans as part of a document called the Disability Equality Scheme (Section 49 A (1) of the DDA, DWP, 2005).

However, there are dangers, as exemplified in the discussion by Oliver and Barton about the impact of feminism:

The very point when women’s studies was accepted as a legitimate academic discipline in its own right was precisely the point at which it seemed to lose its radical cutting edge. (2000, p. 2)

Whilst I believe that disability equality is a long way off from being accepted into the mainstream academic thinking and professional practice, I nevertheless, consider a note of caution is appropriate. Public authorities in education, social housing or health, now speak and write about the ‘duty to promote disability equality’, but in many cases, it could be argued that they are simply displaying well known linguistic dexterity. At the time of writing, legal changes in the UK threatened to weaken or remove ‘disability equality’ altogether under the provisions of the new Equality Act (Disability News Service, 2011; DWP, 2010; Gööding, 2010a; 2010b). Patterns of thinking, changing language and conflicting meanings symbolizes a further aspect of the political zoom. My particular Denkmuster are outlined in the next section, and the personal is related through further biographical reflections.

IDEOLOGY AND DENKMUSTER: FROM THE PAST INTO THE FUTURE

All research is political (Hatch, 2002) and in this section it is important to me to make theoretical and epistemological foundations clear. I will outline my research approach and offer biographical sketches to explore its roots. Critical social theory provided a framework, whilst the main tool for analysis in my research on disability equality was the application of the social model of disability (Barnes & Mercer 2010; Barton & Oliver 1997; Oliver, 1990; 2009; Oliver & Barnes, 2012) to the context of curriculum development and the subject of citizenship (Morris, 2005).
Epistemologically, I drew on and blended a range of traditionally distinct academic fields, with law, education, social sciences, and philosophy. The goal was to construct meaning by examining multiple realities through disabled people’s own voices (disabled voices) and positions (disability voices).

The ideological underpinning of my work was rooted in critical social theory. This was originally developed by the Institute für Sozialforschung at the University of Frankfurt in the 1920s. As a form of thinking it had already been familiar, accessible and relevant in my personal and professional endeavors, since I received much of my education in Germany and in the German language. I applied critical theory (Habermas, 1987; 1992; Held, 1992) that integrated political, cultural, economic, structural and psychological aspects of analysis to a discussion of the material disadvantage experienced by disabled people. This approach created a transformative agenda.

In my thesis defense, viva voce, I was asked by Len Barton about how I had encountered the social model of disability for the first time. This was an interesting question upon which to reflect. I concluded that my encounter with the social model was a disturbing, yet liberating experience, and detail my reasons below.

First, I was studying social sciences and enrolled in a module on the changing experiences of women. New concepts and specialist vocabulary challenged me to think in new ways and in a foreign language (English). Professionally, I met Mike Devenney, Dolly Grievson and Dave McDonnell, all of whom contributed to my later research. They were employed in senior roles in the London Borough of Ealing advancing equality and access. Each person was what I call an ‘out and proud’ disabled role model.

Second, my own impairment effects rarely intruded into the public sphere, and consequently, I was ‘passing’ as non-disabled most of the time to most people, even to myself. With a condition that fluctuated and was hidden, the social model provided a new way of seeing through which to understand my experience of disability in society. I began to foster an ‘emancipated’ self, which was able to connect the personal and political. This helped me later to investigate inequalities in citizenship education, such as the fact that only two per cent of the academic workforce disclosed an impairment or health condition.

Third, many years ago my father, Joe Reichart, became a wheelchair user following an accident. He involved me in discussions, cartoons (such as the one presented in figure 2.2 below) and campaigns through which ways of knowing developed. I began to understand, for example, the meaning of rehabilitation laws Schwerbehindertengesetz, which were structured around impairment categories and based upon the ‘severity of defects’. The law was ostensibly neutral, yet closed its eyes to the material position of disabled people when deciding about the allocation or refusal of appropriate resources, which were necessary to enable independent living choices. I heard the pain in people’s voices as they adopted strategies to help them prove that there were simultaneously sufficiently disabled to qualify for support, yet able enough to take an active role as citizens. For some, the ‘blame’
if they failed, too often rested within their own body or personal ‘inadequacies’: I remember that pain and I remember that anger. Denkmuster formed during those times undoubtedly enabled more radical ways of searching out disabled voices: ways that recognized a personal ‘internal’ zoom that laid the foundations for a critical reading of the law.

Partially shaped by these experiences, I became an ergotherapist at a progressive academy in Germany. Despite the fact, that together with junior doctors we were instructed by some disabled lecturers, most of the teaching remained firmly grounded within an individualized, impairment, deficit model of disability. Abberley (1995) researched the impact of ideology within occupational therapy. He noted that success of client-focused intervention was closely linked to themselves as therapists, whilst failure was often reduced to client resistance. Therapists saw little need to attend equality of opportunity training as they regarded themselves as already progressive in that ‘the demands of the disability movement were already incorporated into the theory and practice of occupational therapists (Abberley, 1995, p. 224). Similarly, at the academy I had learned many ways of seeing the therapist as an ‘expert’ trained to empower the disabled person. The shock and disorientation on discovering the social model of disability as a trained professional was profound and it meant re-evaluating years of knowledge and knowing: professionals do not ‘empower’, therapists do not ‘give’ power, but need to ‘give-up’ power. Disabled people empower themselves.
This section summarizes the social model thinking and outlines three key shifts. A shift from impairment to access was first mooted by Oliver when he changed government research questions, such as ‘What complaint causes your difficulty in holding, gripping or turning things?’ to ‘What defects in design of everyday equipment causes you difficulty?’ (1990, p. 7–8). People do not have a disability, but have impairments or health conditions, and are disabled by barriers in society, which results in lack of access in the broadest sense and includes access to power. Disability is that experience of exclusion.

Over thirty years after Paul Hunt first read out The fundamental principles of disability (Union of the Physically Impaired Against Segregation – UPIAS, 1975), which made the important distinction between impairment on the one hand, and the experience of disability on the other, little progress had been made. The UPIAS principles state that disability is a situation caused by social conditions, which require its elimination; that no one area (such as poverty or education) should be tackled in isolation; and that disabled people should be in control over their own lives. My research findings on themes of citizenship revealed a stubborn insistence on deficit and individual impairments in social policy, rather than access to the citizenship and human rights of disabled people.

In applying the social model, all people (whether disabled people with different impairments or long-term mental or physical health conditions, or non-disabled people who are ‘expert’ in their traditional well rehearsed systems), are invited to change Denkmuster and shift in three significant ways (Reichart, 2007, p. 298):

– Social model: a shift from impairment to access by removing barriers.
– Human rights: a shift from welfare, entitlement or ‘special’ responses to anti-discrimination and human rights values from the outset.
– Political struggle: a shift away from dependence creating structures, to those created and controlled by, with and for disabled people.

Patterns of thought Denkmuster describe interconnected sets of shifts in ideas and beliefs about future possibilities in disability equality and inclusive citizenship. The making of citizenship as an environment of participation and contribution for all is illustrated in figure 2.3, where the expanding circle of self-determination meets access and human rights. Only then can structural change follow and new best practice become embedded, and only then might ‘empirical’ evidence show how inclusive citizenship works. Only when institutional rules and procedures reflect this shift throughout its practice has the socio-political environment been created for inclusive citizenship. Until then we contest ideologies and until then we struggle.

The model of citizenship emerging from these Denkmuster seeks to exemplify an uncorrupted, authentic perspective of disability equality, as inclusive citizenship. Empirically framed case analyses provided the key methodology in this research.
Overall, I adopted a critical theory stance (Kellner, 2003; Scott & Usher, 1999; Young, 2007), which explored the lived citizenship of disabled people. Unlike the positivist, scientific method claims of neutrality and objectivity, a critical approach recognizes that values, in particular citizenship values, are rooted in ‘the personal’. A zoom creates a continuum, in which elements of ‘the personal’ and ‘the political’ are simultaneously engaged. This takes me to the third tool in my research, ‘mash-up’ methodology, which will be introduced next.

**MASH-UP METHODOLOGY: ON HEARING VOICES AND CREATING A NEW SONG**

In applying a personal – political zoom, it was important to me to explore the authentic nature of disability equality by listening to the voices of disabled people themselves, by unscrambling traditional ideas, examining new perspectives and ways of thinking about disability as shaped by the disability movement in Britain and worldwide. However, disabled people’s voices are polyphonic, discordant, and international. It became clear that the sound these voices made was not always comfortable, and by no means concordant: they could be most disagreeable to the unfamiliar ear (figure 2.4). Several questions emerged: Whose voices should be heard? How could they be found? And who should learn to listen?

In an effort to connect disability equality issues to citizenship education, and bearing in mind the demands of ‘practical outcomes’ for teachers of citizenship, I decided to focus on engaging with mostly freely available, accessible authentic voices ‘of’ disabled people. Researching disability equality does not mean having
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to create new data of such voices. Disabled people are, and have been, ‘speaking for themselves’ for years, but the necessary connections, and efforts to listen and seek out voices, have not always been made.

I wanted to find a rich diversity of the many competing, disagreeing, silent, messy, confused, out loud and proud, distant, hidden, organized and lost voices. I decided against ‘representative’ voices of the newly re-emerging, organized system of disability politics in Britain, which was caught up in structural limitations. I argued that it might distract me from thinking freely about future possibilities. Disability voices were taken from both published and unpublished material, as written voices and oral evidence, conversational interview data and research diaries, and observations and personal reflections. They were presented in multimodal fashion with the inclusion of and reference to a small number of photographic or pictorial representations, a DVD, poster campaigns and interactive internet resources designed by young disabled people, online access to video-clips, visual and sound files.

In no particular order, voices were collected from disabled academics to ‘ordinary’ disabled people of different ages and backgrounds, cultural practices, religious beliefs, gender and sexual orientation, and with different levels of political activism. They included individual disabled people and organizations of disabled people, disabled politicians, disabled teachers, trainee teachers, senior citizens, pupils and disabled young people. They included silent voices in the gaps of statistics. I noted under-represented voices in unfilled seats on management boards and in political office; refused voices in cinemas and on buses; and silenced voices outside polling stations. There were disturbing voices and alienated voices buried in legal case law narratives. Illustrative material from Germany and other international contexts complemented the picture at a European and more global level.

Figure 2.4. On hearing voices (e-mail exchange in response to Butler, March 31, 2010).

SUBJECT:
The global voice 4 inclusion
e-Petition to no 10

MESSAGE:
“We the undersigned petition the Prime Minister to: (i) That the UK Government fully supports Article 1 of The Universal Declaration of Human Rights 1948 and that all citizens have a right to be treated with dignity; and (ii) That this right is pivotal in all UK legislation and is applied retrospectively to existing legislation.”

REPLY:
“Oh gawd, more cross (angry) posting. Fuck the UN, fuck the galactic human rights commission. They are all part of the hegemonic conspectus and we survive without them not because of them. When you meet the man with the big stick do you quote law at him, or do you emulate Bruce Lee?”
I wanted to pull out the ‘inner essence’ of disabled people’s voices and run these over themes of citizenship, so that they were continually part of the zoom where the personal voices and political voices were mutually constitutive. The voices were provided by using evidence directly from disabled people (disabled voices) or disabled people’s experiences (disability voices). This was achieved through the development and use of different forms of case analyses, such as embedded case study (Yin, 2003), case law analysis, and case scenarios, which were run over a multiplicity of situations and circumstances exemplifying or illuminating particular elements of citizenship. In that way I created mash-up methodology, thus creating a new sound of disability equality by use of empirically framed case analyses. I shall expand on the idea of creating a ‘new song’ in the subsequent paragraphs, which is then followed by examples of case study approach.

‘Mash-up’ is a Jamaican Creole term originally meaning ‘to destroy’, and in Hip Hop music this term refers to music made up entirely of different songs, different styles or genres usually considered to be incompatible. A ‘Kylie Minogue versus New Order’ or ‘Chris Isaak versus Eminem’ for instance, where one song’s vocals run over the other’s musical lines, resulting in, for example, ‘Papa had a Rodeo’.

Mash-up has been described as ‘the highest form of musical re-contextualization’ and ‘pulls out the song’s inner essence’ (Cruger, 2006, online). A mash-up unsettles, is unexpected, implies no previous connection, at least to the minds of people who ‘know’ the dominant melody. They know it so well. People who are ‘expert’ in their traditional well rehearsed systems are invited to change Denkmuster to hear a new song.

A mash-up version seems wrong, awkward, challenging: almost threatening. It is in this unsettling, challenging edge that mash-up methodology is akin to applying critical theory. To the purist of tradition (in music as elsewhere) the mash-up version does not appear to fit together, such as hearing the distinct voice of Annie Lennox over a drum ‘n’ base musical line, or the ragged Eminem over loved Beatles melody. However, the present generation listens to the song as one creation, one entity, and one complete whole new sound. Mash-up implies something new has been created. In this way I sought to present a new song that respected disabled people.

Mash-up methodology produced a perspective with changed Denkmuster that was completed by the foregrounding of disability voices. I used a new set of vocabulary to express these ideas, for example, foregrounding happens when disability voices are run over a theme of citizenship. If, in citizenship education as elsewhere, we do not hear that voice on every page, then the complete ‘whole’ version of the song has been corrupted. In this vein, the ‘rip-off’ of which Oliver speaks in the opening quote is a form of corruption. To illustrate the corruption that occurs in traditional citizenship discussions which fail to run disabled voices over its themes, a brief example is offered.

In the introductory chapter of my thesis, I wrote about constitutions. I argued that despite different strands, citizenship was primarily a legal concept linked to a constitutional framework for nations. Constitutions contain the ground rules
of government, they define how the state can exercise its power and the role of citizens in this regard, and they identify how money is to be raised and prioritised for spending. Constitutions elaborate on rules and principles of living together in a civic society and the nature of these rules change over time. This changing nature of constitutions can be exemplified by two examples, the first focuses on the Treaty Establishing the European Community – EEC Treaty (as amended) (European Union, 1957), and the second considers an Article in the German Basic Law (Grundgesetz der Bundesrepublik Deutschland – GG, 1994).

In 1957, the Treaty Establishing the European Community (European Union, 1957) not only created a trading community, but also established ‘Citizenship of the Union’ in Article 8 (1). The treaty proclaimed in Article 8 (2) that citizens ‘shall enjoy the rights conferred by this treaty and shall be subject to the duties imposed thereof’. Disabled people are citizens. They have organized themselves to have a voice in Europe. The aim of the European Disability Forum (EDF) is ‘to represent disabled people in dialogue with the European Union and other European authorities’ and its mission is ‘to promote equal opportunities for disabled people and to ensure disabled citizens’ full access to fundamental and human rights through their active involvement in policy development and implementation in the European Union’ (EDF, 2006, online). The president’s address echoed UPIAS fundamental principles:

Nothing about disabled people without disabled people is the motto of our movement, but also a basic principle of democracy. We will therefore continue to work at all levels to make sure that civil dialogue becomes a permanent reality in the region. It is a right we are asking for, not a favour. (Vardakastanis, 2006)

Basic human rights are enshrined as basic law within the first nineteen Articles of Germany’s constitution (GG, 1994): ‘The dignity of man shall be inviolable. To respect and protect it shall be the duty of state authority’ (Article 1). To this extent, Article 3 deals with equality before the law: ‘no-one may be disadvantaged or favoured because of his sex, his parentage, his race, his language, his homeland and origin, his faith, or his religious or political opinions’. With growing political pressure from disabled people, this provision was finally amended in 1994 to include disabled people in Article 3 (3): ‘Niemand darf wegen seiner Behinderung benachteiligt werden’ (‘no-one must be disadvantaged on the basis of impairment/disability’). Article 3 (3) has been interpreted by disabled activists as meaning: ‘Menschen mit Behinderungen ein Leben ohne Barrieren zu ermöglichen’ (‘to enable people with impairments a life without barriers’) (Dahesh, 2000; 2004; Degener, 1995; Heiden, 1996; Hermes, 1994). Article 3 (3) is phrased in such a way as to allow for positive discrimination and more favourable treatment for disabled people in order to correct past injustices and remove barriers resulting there from.

Significantly, therefore, within mash-up methodology I needed to run disabled voices over the theme of constitutional legal rules. I could not talk about Article 8 of the European Convention on Human Rights (Council of Europe, 1950) without
including the European Disability Forum in their own voice. I could not look at German non-discrimination clauses, Article 3 (3) of the German constitution, without citing disabled people whose political efforts had created and whose writings gave meaning to the otherwise abstract legal provision. The emerging picture was more than the two parts: constitutional legal rules on the one hand; and disabled people’s responses or perspectives on the other. Instead, to run disabled voices over the theme of constitutional legal rules resulted in a fuller version of citizenship in the European Union, one that showed disabled people as constituting and actively engaging, first left out and later inserted in official text, as citizens struggling and campaigning in political discourse of the European Union.

A mash-up hears disabled voices not as additional ones to existing tunes, but as a constituent of a new and different song. Without this approach (running voices over themes), there is no ‘pure’ or neutral or objective approach to citizenship. Without it there is no ‘professional’ view of constitutional issues of the European Union, only a corrupted one. There is no ‘European Union’ without disabled people, there is no citizenship education without disability equality.

In my research, both quantitative and qualitative elements were used to frame and run disability voices over themes of citizenship. I applied three varieties of case study method in a ‘teleological’ sense, primarily to illuminate, to reveal not so much inadequacies, but a different picture. The aim was to connect disability equality to the concerns of educational practitioners in citizenship education. A dichotomy of quantitative and qualitative methods was not helpful as it failed to provide a meaningful distinction when finding out about disabled people’s lived citizenship experiences.

For instance, in the case study ‘AA Centrica’ disabled people’s action was embedded in a broader context of employment structures. Several stories were concurrently presented: disabled people’s voices, disabled workers ‘specially recruited’, disabled employees later sacked, voices who were exercising political citizenship through protest and demonstrations, organised forms of disabled people’s voices through the Disability Rights Commission and Trade Unions, as well as disabled people’s action in taking recourse to the law. All of these different voices were run over the expanding and contracting economic pulse and context of the business (AA Centrica) over a period of several years. To complete the mash-up methodology the case analysis was further illuminated by reference to the voices of disabled academics in critical writings (for example, Abberley, 2002; Oliver, 1996; 2009; Oliver & Barnes, 1998).

Following Yin, the embedded case study is an empirical form of enquiry, where the goal is to describe the features, context, and process of a phenomenon (Yin, 2003). A critical analysis, however, and the rigorous application of the social model of disability, go beyond description and begin to make sense of facts, narratives and case presentations. In this way, material and discussions, like the AA Centrica case study, hears a polyphony of disability voices. I argued that mash-up material as in AA Centrica, will teach citizenship learners a way of thinking about how the
law functions, about economic exigencies, about the opening up or closing down of opportunities and about the impact both law and economy has on the active citizenship of disabled people in different social situations. Without disability voices citizenship teaching in economics, law and social order is corrupt. For example, in 2002 citizenship became a statutory subject in England for 11 to 16 year-olds and part of a non-statutory framework at primary school (from age 5), yet five years later Developing citizens whilst claiming to provide ‘an authoritative collection of key papers’ (Breslin & Dufour, 2007, back cover) failed to include disability equality.

I sketched many disability voices over a particular citizenship theme, such as the theme of ‘economic participation’, ‘political engagement’, ‘autonomy and choice’, ‘democratic participation’ and ‘identity and belonging’. During the collection of data, I was unclear about the overall shape of the PhD. It was an organic, accidental process that came together during the writing-up phase. The totality of single and embedded case studies, together with voices of disabled people from a very broad range of empirical sources performed the function of triangulation and thus increased the validity of the study. This richness provided persuasive evidence of both the need for and a method of connecting disability equality to citizenship education. The main activity was ‘ideological critical thinking’ within the personal – political zoom of active involvement of disabled people. As Oliver observed, ‘to say that I don’t have an ideological position is in fact an ideological position. It’s bizarre that most people don’t recognize that’ (quoted from an interview by Allan & Slee, 2008, p. 58).

Significant impact of my research findings in the teaching and learning of citizenship in schools remains illusionary. When the ‘citizenship, diversity and identity’ strand was reviewed in the National Curriculum, disability was again left out. I fear that these gaps cannot be filled simply by having a ‘disability and citizenship’ pack on the shelves at school or by running ‘disability awareness’ sessions, because whilst resources have been developed with and by disabled people, they are not always consistently framed within the social model. Significantly, even if they were so intentioned, they failed to penetrate the core of professional practice or institutional arrangements. For instance, the extent to which a teacher is or is not grounded in the social model of disability, becomes an important determinant for the way children’s imagination can be recruited and their understanding and emancipation on disability equality enhanced. The question is not so much whether a teacher is disabled, given the low numbers who disclose an impairment or health condition, but which perspective or understanding that teacher brings with them, the level of their ‘emancipated’ self.

INSIGHTS ABOUT MY RESEARCH GAINED AS A RESULT OF WRITING THIS CHAPTER

Authenticity is the challenge for disability research and to address this I developed a mash-up methodology with three key elements: transformative agenda, relevance to the lived experiences of disabled people and significant impact. The application of
running polyphonic disability voices over controversial themes tells us more about the structural forces in society than any one of these voices could do by themselves. In combination this mash-up offered a rich tapestry of authenticity, which empirically drew together a wide range of data sources and provided a context for patterns of thinking about citizenship issues.

On reflection, I regret that at an institutional level the final element remained largely illusionary. Stubborn structural forces counteracted significant progress and, in fact, there were signs of regression: in other words things were getting worse for disabled people. Yet, I experienced, how liberating research and the imagination of future possibilities, had the potential to empower disabled people (people with impairments or with long-term health conditions).

Disabled people did not agree with each other and there was a mash-up of voices. Running over the political citizenship themes were disabled voices involved in, or promoting, a broad spectrum of political campaigning methods, whether close to or away from government: protests, political lobbying, education and persuasion, poster campaigns, democratic participation, voting behaviour, self-organisation, internationalism, recourse to the law, direct action and civil disobedience. Others were simply keeping their heads down. I concluded that there was no ‘one’ voice or ‘true’ voice or ‘objective’ voice. In the same way as dissonance, a note or chord outside the prevailing harmony, was vital in understanding the overall tonal and harmonic quality of music Klangqualität. Apparently conflicting or contradictory voices were necessary in completing the mash-up of voices over a theme of citizenship.

The cartoon by my father symbolizes various successful dissemination approaches. I used Justicia to support human rights training as well as presentations given to research students on the personal – political zoom in disability equality research (Reichart, 2009; 2010). I gave permission for Justicia to feature in training material developed and disseminated with, for and by disabled people, such as on the front cover of Disability is a human rights issue: A guide to human rights for disabled people (Leicestershire Centre for Integrated Living, 2010). The cartoon also greeted visitors to the Disability Awareness in Action (DAA) internet page on justice, whilst I was researching and editing for this international network on disability human rights stories across the globe. In other words, key outcomes of my research Connecting disability equality to citizenship education (Reichart, 2007), resulted in my own re-positioning: moving closer to grass-roots activism and further away from academia, of writing simultaneously from ‘with-out’ academic institutions, whilst not aligning myself to ‘within’ a particular disability organization.

Dissemination continues to remain a challenge. Widening the ‘emancipated knowledge’ reach, in particular on human rights and the role of law, is envisaged through disability politics, information networks and disabled people’s organizations but largely ‘out-with’ academic institutions. There is a weaker dissemination, that keeps me earning a living: Justicia with a mash-up of disability voices is used as a methodology in training sessions and presentations to health and social welfare
professionals, housing experts, board of directors of public or private services, government departments, and leaders in the education sector. In this way, stubborn institutional barriers continue to be challenged.

A FINAL WORD

This timely reflection has reminded me of the power of direct experiences with ‘out and proud’ disabled people. It has warned me of the potential of being crushed under the weight of existing structures and power relations. We need to join together in solidarity and action to create a ‘new song’. For people with and without impairments or long term health conditions, thinking is a necessary but not sufficient element in our liberation.

Unfinished Business: What is left to do, other than to start again at the beginning?

To engage the personal – political zoom in a way that both respects diverse personal narratives of impairment or long-term health conditions and asks critical questions of the law, within its socio-legal context, as it continues to fail disabled women.

To apply the mash-up methodology to constellations of power in our ‘throwaway’ consumer society, so that disabled and disability voices energize transformative knowledge, in order to challenge the effects of the expanding and contracting pulses of recession.

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