

REHABILITATION IN PRACTICE

Producing boundary-breaking texts on disability issues: the personal politics of collaboration

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Purpose: This article explores the reflection on a process of inter-collaborative team work to produce a photographic book on caregivers' experiences of parenting their disabled children. The team of authors consisted of members with diverse backgrounds, including media studies, social science and photography. The purpose of this article was to explore and gain a deeper understanding of the process of boundary breaking, one which is important if we are to develop new knowledges and new ways of thinking about disability. **Method:** In-depth interviews were conducted with all contributors to the book. **Results:** Themes emerging from the interviews include the existence of different worlds, crossing boundaries, questions about expertise, conflicting hopes and expectations, and the ethics of anonymity. **Conclusion:** An account of the anxieties, the frustrations and rewarding aspects of the collaboration is provided. We conclude that "us" and "them" categorization permeates our thinking. It characterizes some of the most simplistic thinking in the world of disability – able-bodied vs. disabled. In reality, there are no such categories, we all reside along a highly differentiated continuum of changing states of impairment and health. If we open ourselves up to this reality, we can meet one another and draw on one another's knowledge and experience.

Keywords: Boundary breaking, inter-disciplinary collaboration, meaning-making

Introduction

The book "Zip zip my brain harts" in which the experiences of parents with disabled children are presented in photographic form as well as through social science research is an attempt to create exactly the kind of counter-hegemonic textual space that disability studies calls for. However, the process of working across media as well as across academic disciplines was

Implications for Rehabilitation

- Collaboration between able-bodied researchers and disabled people and their families holds the potential for producing new perspectives on disability and rehabilitation.
- These collaborations may be emotionally challenging and they hold possibilities for a range of conflicts.
- Dealing with these challenges conflicts openly and honestly may lead to a deeper understanding of the issues at stake in disability and rehabilitation.
- We need more examples of reflection on innovative collaborative processes.

at times challenging – a process we reflect on here. Although there were other differences among team members, for example in seniority of position and gender, it is the disciplinary differences between us which emerged as most significant.

It is worth stating at the outset that our intention in both the book we discuss and this article is to open up academic writing to other audiences, to all people whose lives have been touched by disability. This is the reason we do not engage in extensive discussions of the academic literature. This article is a reflection on process, on the experience of collaboration; it is an exercise in reflexivity. The purpose of this article was to emphasize the importance of reflecting on the process of innovative research production. We are aware that we enter into this conversation about our experiences of writing a boundary-breaking book as non-disabled people, and hence we make no claim in the book, nor in this article, that we are the "voice" of disabled people. In a similar way as Goodley and Tregaskis [1], and Butler et al. [2] argue, in foregrounding Angela Buckland's (the photographer in our project) experience of parenting a disabled child, we value and draw on the

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work of an individual whose expertise is located in her personal experiences of disablement, to inform our collaborative project. The concept of boundary-breaking is multi-layered. It refers to the negotiation of the boundaries between academic and popular knowledge; it refers to the foregrounding of the subjective experiences of disability; and it refers to the incorporation and negotiation of the varied priorities, beliefs, values and ideologies held by different team members as a result of their investment in different disciplines.

Disability studies as a discipline is one which tolerates and, indeed, foregrounds diverse knowledges [3], a process that we have found to be enhanced in the challenge of producing a book which incorporates a photographic exhibition and an academic discussion of disability politics. Disability studies, within which we would position our interdisciplinary text, recognizes that traditional hegemonies of knowledge require subversion, that important voices have been marginalized in discourses on disability [3]. Within the social model of disability and subsequent revisions of this model, there is emphasis on the importance of moving disability studies beyond third-person discussions about disabled people to a situation in which there is dialogue and debate about disability, with the voice and experience of disabled people at the core of these discussions [4]. Within the field of disability, much of the writing has been dominated by health professionals charged with “treating” or “providing therapy for” disabled people, and there is by now an established literature demonstrating how much well-meaning writing and action by health professionals can contribute to further marginalization and oppression of disabled people [5].

The “nothing about us without us” slogan [6] of the international disability movement is reflected in policies about disability-related research and publication. This emphasis on plurality of perspectives and methods and on participation of formerly marginalized groups in writing about their own concerns are not unique to disability studies – there are similar concerns, for example, from the fields of feminist scholarship, black studies and queer theory, and certainly from the burgeoning field of postcolonial studies [7,8]. In all these fields, there have been attempts to claim the centre of the discipline as one which should be owned and controlled by groups who by word and deed have been marginalized, spoken about, told what is in their interests.

A core feature of this turn in disability studies and similar disciplines is that of self-representation, and in this regard alternative avenues and processes of expression become important. It has been repeatedly argued that it is essential that disabled people themselves claim the space to talk about disability and to represent disability issues [9]. Processes of “othering,” which involves accentuating differences between self and other in a way that discriminates against the other, are suspect and problematic and are argued as less likely to occur if disabled people themselves are given a voice in representing themselves. This is why it was so important in our book for the experiences of children with disabilities to be portrayed by a mother of a disabled child. The term in social science that best describes the photographer whose work is at the heart of the Zip zip project’s photographs is the creation of a visual version of “collective biographies” [10].

At first glance, her process of gathering information overlaps in some ways with participant observation methods, but with one key difference – Angela was a participant herself, making the process so much more intimate and rendering it quite distinct from standard social science practice.

A related issue to othering, especially given the worldwide history of disabled people being denied access to equal educational opportunities, is the importance of finding new outlets and forms for academic work. Traditional academic journal writing, by its very nature and conventions, denies access to many people unfamiliar with the conventions and requirements of the genre. Even when disabled people write in academic journals, they are usually required to write in such a way that the vast majority of people, and indeed, the vast majority of disabled people, may find it difficult to access or understand [11]. This is not always because academic writing is of a more complex intellectual level than more popular writing but also because of conventions which are obscure to those without a particular educational background. We have found that the combination of different genres and media – of photographs and academic analysis– can be more accurate in expressing a complex set of knowledges than either mode of expression could do on its own.

Having established, though, that part of what disability studies is and should be about is the crossing of boundaries between the more traditional academic worlds and those of the lived experience of disability, how in practice do we move forward into this new domain? In this article, we report on our experiences in one such attempt to contribute to disability studies in a different way, to collaborate across disciplines and investments in disability and to create a product which would be both accessible and helpful within the world of disability.

Background to our project

Angela Buckland is a well-known South African photographer (see www.angelabucklandphotography.com) who has been involved in a number of high-profile projects including producing photographs for a landmark book in South Africa’s history, focusing on the new Constitutional Court [12]. Angela has produced a number of photographic works concerning issues of parenting and disability. At the time that Leslie Swartz was approached to work with Angela, he was on secondment at the Human Sciences Research Council (HSRC), South Africa’s national social science research body, from his university position, and he had recently set up the research focus on disability studies at the HSRC.

Two research assistants, Amelia van der Merwe and Kathleen McDougall, worked with Angela and Leslie to produce text for a book which would provide a wider audience for Angela’s photographs than photographic exhibitions could do. The writing of the text also provided opportunity for broadening the impact of the photographs. Amelia produced a literature review on the topic of parenting disabled children. Leslie and Kathleen conducted interviews with parents. Kathleen produced the first draft of the text, which incorporated Amelia’s literature review, and all four collaborators edited

and reworked subsequent drafts. The parents we interviewed were sent copies of the last version and asked to comment specifically on the sections which dealt with their interviews. The changes they suggested were incorporated into the final version, which then went through the usual editing process prior to publication.¹

The project took 2 years to complete, a process which included having to raise additional funding. It was the product of an unusual collaboration – between an artist, two psychologists, and the first author, who came from a media studies background and is now an anthropologist. The project is also the product of a particular context and moment in South African social science research, which we outline briefly below.

The HSRC has a history intertwined with apartheid social science, and the relaunching and revitalizing of the HSRC in the post-apartheid era has focused on what the HSRC calls “Social science that makes a difference,” not only, as one might expect, in relation to race but also to a more broadly defined social inclusion. It is important to the current HSRC to be responsive to the needs of all South Africans and to redress a history of widespread exclusion from professional knowledge and its benefits. In South Africa, of course, the major redress issue is that of race, but disabled people, most of whom are in any event, in South Africa as elsewhere poor and black, have also faced, and still face, their own issues of exclusion. Given the fact of the exclusion of most South Africans from quality education for generations, the HSRC is also interested in ways in which social scientists can communicate accessibly with the public. One way in which this is addressed is through the HSRC Press, which, although independent of the research facility, supports the dissemination of research analysis through conventional hardcopy publication and also through making texts available at no cost electronically on the Internet.

Thinking about the process: the genesis and method of this article

The process of producing the book was anything but simple. All participants, at different times, were taken unawares by the depth of our emotional reactions to the process. We wanted to understand the process better – the unwritten subtext of boundary-breaking, the anxieties, the frustrations and the rewarding parts of the collaboration. We learned viscerally what we had known intellectually before – that one of the functions of boundaries between different ways of working and approaching emotionally laden issues is to contain anxieties [13,14]. We wanted to understand better, though, what we had been through, for ourselves, and also to open a debate about which we could find little in the published literature. The purpose of this article was to explore and gain a deeper understanding of the process of boundary breaking, one which we believe is important if we are to develop new knowledges and new ways of thinking about disability.

¹The book *Zip zip my brain harts* (McDougall et al, 2006) can be purchased from the HSRC and is also available for free download in pdf format at <http://www.hsrcpress.ac.za/home.php?cat=5>.

Once the book was completed, therefore, we commissioned a research assistant to conduct in-depth interviews with all four contributors (the photographer and the three authors) about the process of producing the book. The researcher, Hester van der Walt, is a very experienced qualitative research methodologist and interviewer who herself has an interest in boundary making and breaking [15]. Hester interviewed Amelia, Angela and Leslie each individually face to face, and Kathleen through videoconferencing as she was completing studies in anthropology at the University of Chicago. All interviews were audiotaped and transcribed.

This article was drafted by Leslie and Amelia and was then sent to all other participants for comment, with the offer that if they wished to contribute to the article they could join as co-authors.

Theme 1: different worlds

They talked their own language.
– Angela

The book brought together the worlds of psychology, photography and media studies. Each team member had his or her own professional identity, and with it came a unique conceptual world which determined his or her ways of understanding and experiencing the production of the book. There were also other concrete differences between team members. Angela, the photographer, worked free-lance, while the social scientists were part of a large organization, which Angela felt protected and insulated us. At times she felt that collaboration with an institution such as the HSRC was intimidating, stifling and frustrating:

As an individual I am responsible to myself, I am a free agent and I am self-employed. The team that I was working with, the HSRC, is accountable to an organisation. They talked a different language at the HSRC and it is quite formal, and I was intimidated by academia. They are overwhelming and I am a single person dealing with this huge organisation and infrastructure. I did not have any of that. I do not mean that unkindly, but for someone who is independent all this is quite frustrating.

An additional source of anxiety for Angela was the physical distance between her and the rest of the team, which she felt left her excluded from important conversations. Angela describes her sense of isolation as follows:

I was sad that I was in Durban and the team was in Cape Town (the two cities are 1271 km apart). That was a great loss because there were conversations that were absolutely fascinating which I had not been able to be part of, so I always felt isolated. Working by myself is quite hard and sometimes one's emotions can get over active and destructive. I am very aware of these things but I was so hungry, hungry to be part of that information and just to talk, to talk, talk through it.

Theme 2: crossing boundaries

It's been impossible, really difficult working with Angie, and I've spent a lot of time being very angry with her as she knows, but I would work with her again, because what an opportunity! Just look at what she is able to do!

– Leslie

All members of the team were aware that they were becoming acquainted with another conceptual world and of the importance of respectfully encountering difference. This process parallels the process of conducting disability research, particularly when coming from an able-bodied position – it involves being open to and tolerant of different points of view, different priorities and values, and incorporating these differences into the research product. For our team, this process raised conflicting feelings; both excitement, but also challenging feelings such as anger and frustration at accommodating different opinions, priorities and plans for action. Although not equally difficult for all members of the team, Amelia found it challenging to cross over into another conceptual realm without feeling defensive of her professional territory:

It was very interesting for me, to start working with ...with an artist! And also with someone like Kathleen whose leanings are anthropological and I see myself as an empiricist, a hardnosed researcher! And Leslie is wonderful because his mind goes almost anywhere and everywhere, so I do find him inspiring because he crosses those different worlds with relative ease. I think he has awareness when he is crossing and awareness when one of us, say Kathleen or Angie or I, would start getting defensive about something. Then Leslie would feel the same way but he would be aware and there would be this talking around it and through it. I cannot speak for Kathleen, but for me, I learned a lot from that process, and how intolerant I am of different ways of doing things. I think it is the old thing that goes with any team work but I think the differences between team members were bigger here than they are normally, here you got up close and personal with your own intolerance in quite an intense way!

For all members of the team there were moments where we questioned, as Angela put it, “what is your role, what is the boundary?” All members of the team felt uncertain where their ownership of the project began and ended, and consequently, where our rights to influence its outcome began and ended. Because of this, it felt that for some of the time, we were floating in the structureless no-mans-land between disciplinary boundaries – a very uncomfortable place to be, because there are no clear guidelines for action.

This process is central to interdisciplinary collaboration. It involves the shedding of each team member’s professional persona and transitioning towards the “other” team member’s unknown conceptual or disciplinary world with a willingness to receive and to try to understand another “language.” This is a very challenging process because it requires embracing fear associated with the unknown and being willing to be vulnerable – not all-knowing, propped up by rules and guidelines and professional codes. It involves reconciling oneself to the possibility that there is a greater truth than just that which comes from one’s own body of knowledge and experience.

Sometimes, the outcome of such a transition and attempt to understand is unsuccessful. For Angela, some of the differences between art – a largely creative, aesthetic and applied endeavour – and psychology – a science – as disciplines were irreconcilable:

Psychology has strict boundaries and rules. Artists just do not have any rules and we break them! They are there to be broken and that is what I love. And that is who I am!

They (academics) don’t have the freedom and flexibility to move... So I think, what a lost opportunity...

Theme 3: who is the expert?

Who is considered the “expert” is central to disability studies as a discipline and is based on the movement from biomedical/rehabilitation experts to those who have lived with disabilities, and as such are experts of the lived experience of disability [1]. This transitioning of expert status is important in our discussion of crossing disciplinary boundaries. Each of us had expertise in different areas and had claims over different aspects of the collaborative project.

The project set up complex ownership dynamics. This was triggered by differences within the team about what was considered a priority in the project (which often differed from one team member to another) or what perspective should be favoured in the text and whose decision it was, as different aspects of the book “belonged” to different team members, although boundaries at times were blurred. Each of these struggles was reliant on who was considered the expert, and because each member of the team was an expert in a different area, it caused significant challenges. Leslie describes an “iconic meeting” where differences in disciplinary priorities were made clear:

Angie held up two pieces of paper, which looked completely identical, to me, and she said “if we print on this kind of paper, I can live with it, but if we print on this kind of paper I absolutely can’t live with it”, and to me they looked completely identical! So, a lot of people have commented on how beautiful the book is presented, and it is beautiful, but I didn’t have a clue. I am very proud of it, but this has been a source of tension between us, and between Angie and the publishers.

Leslie also describes making a decision to shift a strong social model perspective taken by Kathleen, the first author, to a more nuanced perspective which was more sympathetic towards medical practitioners, despite the conflict over ownership of the theoretical orientation of the text that it caused:

Amelia and I are from a psychology background and Kathleen comes from a background of media studies. We realised quite quickly that we were from quite different conceptual worlds. Her take on the way that she took the data from the parents was very different from what I wanted. What she wrote was very judgmental of doctors. This is quite common in the disability studies literature, and I felt incredibly strongly, I didn’t want that. So there was quite a big overwrite from me. Kathleen really wanted to understand what I was on about, but she found it hard in the beginning. She wanted to write her draft on her own. She likes to work independently. So there was always a sort of tension – Amelia and I versus Kathleen.

Ownership conflict also occurred over the meaning or interpretation of the images. The social scientists felt that Angie held certain views about the interpretation of her images (as the artist, and thus, the expert), and they felt that in some cases, their interpretations would be difficult to articulate for fear of entering into territory which they did not fully understand.

As noted by Leslie:

It’s very hard to say to Angie, well, when we look at these photographs actually, we see something you didn’t intend.

He goes on to say,

...there were difficulties. In the end I mediated between the two positions, but I had to eventually say that we may have misinterpreted you, but we read your photographs in a different way. For instance the panel where Kathleen read the image of a woman with a cross as signifying prayer. Angie felt very strongly it is not prayer, it is only about anger. I can't remember how we resolved it, I said what we were prepared to put in the text, is that we saw it this way, Angie intended it differently, but that's what happens with art. Then there is the question, who is the expert here? In readership theory we hear "don't trust the teller, trust the tale". But when you are dealing with stuff that is so emotional, it is hard to say to Angie "if we look at your work we see something that you did not intend", but we had to say that to her.

Reflecting on these issues later, Angela said,

We were talking to an audience and I was sensitive about the way my work was being written, by people who were not authorities on critiquing photography. The team was welcome to articulate their opinions but for print I feel it was reasonable to retain a degree of guardianship over that process. And yes, it was a struggle between us and it helps to reflect and understand that struggle now!

From Angela's point of view, furthermore, "academics are very territorial." For her, this book was,

... my concept, my baby. And that must be annoying from the researchers' point of view. So I respect and understand that. It must be very hard. But that is the beauty as well. Good products are always hell...It's like delivering a baby.

This book was for Angela her "baby" in so many ways, and one can only imagine how difficult it must have been to share any part of such deeply personal territory.

Collaboration in the book involved a great deal of sacrifice and compromise from all parties. One of Kathleen's initial hopes had been to "create a kind of visual archive, to show how revolutionary it was, what Angie was doing" – to take the reader through a photographic history of the portrayal of disabled people. However, due to lack of funds, Kathleen was not able to include nearly as many photographs as she would have liked and had to make do with what the budget allowed.

Theme 4: conflicting hopes and expectations

One of the core debates during the preparation of the manuscript was who the readership would be – the public, academics and/or the art community. For Angela, it was important that the quality of the presentation ensured that the book looked like an "art book," while the social scientists wanted to ensure that it was a public interest book "for everyone." Leslie comments:

The question of audience is a major issue here. We've had the text overwritten and the editor changed quite substantially something that I said. I had written that it is a problem saying that a book is for everyone. Then it falls between stools. And he changed it and said "we say with emphasis that this book is for everyone". The HSRC press appointed him and he did a really good job. But it became increasingly clear that Angie, in addition to being concerned about the rights of parents of children with disabilities, and children

themselves, in some sense I feel that Angie's primary audience was the photography and the arts community. So she brought on a good designer, a friend of hers. What the book looked like was important to her, to the extent that there was substantial disagreement on this.

For Angela, sourcing funding to meet her presentation expectations was paramount and it delayed the completion of the book significantly. For both Angela and the social scientists, the delays, and the reasons for the delays (continual searching for funding), caused a great deal of frustration.

Having sourced funding from the art sector, Angela had an expectation that the book should speak to this audience, among others, but felt powerless to ensure that this would happen:

I managed to source R150,000 from the artistic community. I felt that I had a stake in it, but it was clear that the HSRC needed that power and they managed it from their side. This was about power and resources. I still see them as having a lot of resources and I did not have any. I felt quite undermined. If there is a next time it cannot be like this. This undermines the role of art and of the profession and I was naïve.

Angela raises the issue of different worlds again, and how that relates to divergent expectations and frustrating consequences:

The world that I come from...I don't think they realise the world that I come from. How I operate. I suppose I had an expectation, and they may have had a different expectation. Maybe it comes down to different expectations. This big organisation, that had the publishing department, that had the this, and had the that, that's useful, we can't get things done without being well resourced – but the freedom lows, the creativity lows...

Interestingly, Leslie and Angela's priorities – the need for the photographs to communicate to their audience(s) the realities of the families lived experience of disability – eventually coincided, as Leslie realized the following:

I feel that my visual literacy has changed. I will tell you one thing that happened to me. When we had the exhibition with the way in which she presents the photographs against light boxes, in the image of the stickytape collection bib shirt, I saw something for the first time. In the sewing there are some unfinished ends. When I saw it on this huge thing it had an enormous emotional impact on me. That bit of detail captured for me the incredible capacity that Angie has to capture the intimate. It felt unbearably sad for me, because her mother did this. The thought of her, how she must have bitten or cut off these threads, it just touched me in a powerful way. I felt there is so much more here. We haven't even started. I thought I am so lucky. I think why I love this section so much is coming from a family with disability, that mixture of concealment as an act of love. Denial as an act of love. Somehow Angie has managed to articulate something which I don't know I would ever have been able to articulate. And I don't know that I would have found it in words.

Theme 5: a power struggle: the ethics of anonymity

With the call for more voices to be heard in disability studies and, indeed, in other forms of empowering or decolonizing methods, there is commonly an assumption that there exists,

usually at some hidden or subjugated level, a voice that accurately portrays the experience of the excluded or the oppressed [16]. What is less clear, though, is how we get to this voice. Indeed, if we take seriously the argument that all texts, all “voices” are profoundly shaped by a range of forces and power dynamics, then the goal of reaching a more “authentic,” or “giving voice to” those who have been voiceless (a worthy goal of emancipatory practice) begins to disappear the closer we get to it. The social scientists among us, in retrospect, held something of a naive view about what working with an “insider” would mean – we implicitly expected that parents of disabled children would give us what we thought would be a unified picture of a singular experience, however much we consciously knew that this very expectation of authentic homogeneity was itself a form of discrimination. Some of the difficulties with this book, therefore, are difficulties we experienced when Angela and the other parents did precisely what on the surface we wanted them to do – to talk back to our methods and assumptions and to respond in ways which we had not anticipated. One of the unexpected ways in which parents reacted was to the social scientists’ wish to protect their identity.

Three of the core principles of ethical conduct in psychology are anonymity, confidentiality and informed consent. The reasons these principles are adhered to are to protect research participants from exploitation or harm of any kind. However, one of the greatest debates to occur during the process of producing the book was over-protecting the identities of the children in the Angela’s photographs.

As disciplines, photography and psychology view the disclosure of identities; in particular, the participants names in the text; entirely differently, and the two positions were irreconcilable on this issue. For Angela, the decision to protect the children’s identities was the outcome of a power struggle between the two positions, and she describes a tug of war involving a distinct power differential, misunderstanding and hurt (see below). Although Angela says that she wanted her story to be communicated from a “voice of legitimacy,” and there were some benefits to this, the manifestation of the power differential felt by Angela between herself and the HSRC researchers which accompanies this “legitimacy” caused a great deal of distress and disagreement in this instance:

...the decision was taken that they would protect the families’ identities to protect the children and that they would use my name. But the families were not consulted about that decision! The HSRC thought that it was the ethical thing to do, but some of the families were hurt by that! They were not going to object to that, they were fairly powerless in a way because they were dealing with serious academics here. I did not take it up, but I just know that one person was very hurt because why would they not use her name, she was an adult, and this was important to her. That is a power issue and I regretted that, but I left it alone because I realised that it was territory. I felt it was not negotiated and I felt uncomfortable about the power that they assumed and adopted.

For the social scientists, protecting children’s identity was an ethical responsibility, because, as Amelia says:

I was concerned that in this book children are being identified and their parents are saying personal things about them and how would

they feel about that ten years down the line, or however long. “If I recognise this bit here, and I’m sure my mum was the one who said this.” I feel very strongly that children should have a choice in where and how they are portrayed. And Angie felt very strongly that in these photographs there was no need to mask identities at all because, were we saying that disability is shameful? For me that was not the issue. That was not what I was trying to convey.

For Leslie, protecting the children’s identities was bound up in a tradition of representing disabled people as spectacles or “freaks”:

There were a number of things...Angie felt much more comfortable with talking about the families in a very public way than we did. I think what Angie’s original idea was to present each family as a case study and it just absolutely went against the grain for me because it kind of reproduced this media idea of disabled people being a spectacle.

The sense that different team members were talking different languages was most stark over the issue of protecting children’s identities. For the social scientists, identities were being protected because children did not have a choice in how they were being represented in their families’ stories and to prevent the unwitting reproduction of disabling media traditions. Consequently, for the social scientists, it was mainly a children’s rights issue. However, for Angela, anonymity was synonymous with shame. She felt that concealing identities was sending a message that disability is something to feel ashamed about, to hide. That it was about not telling the full truth. It was a very challenging divergence in points of view.

Angela says of the social scientists’ decision to insist on anonymity:

That is academia when it starts suffocating itself! There is nothing untruthful. There is nothing to hide, nothing disrespectful. I would never want to disrespect any of them (families). If I was doing them a disservice in any way, of course then they would have to be protected. Maybe they should have been consulted. I think there are families who would have preferred anonymity, but that was not negotiated and that was a power issue.

Some scholars [17] have warned that researchers may have an (arrogant) tendency to assume that they know what is best for their research participants and unilaterally make decisions on their behalf which may not, in fact, be in their best interests. Such an approach is also at odds with the kind of egalitarian-friendship relationships Angela had with the families, and the greater power differential that traditionally exists between researchers and researched, as there was between the social scientists and the families of disabled children. Having the social scientists assume a powerful position with regard to ethics, and Angela conveying and discussing this with some of the families, who felt that they had no choice, complicated social relationships between Angela and the families and Angela and the social scientists. Angela’s agitation and the families’ reported hurt may indicate that we should have been more transparent about why we assumed our position and the reasons for our decision.

Problematizing the mistaken perception that the social scientists in the team were concealing children’s identities

because of shame surrounding their impairments is understandable. Shaming has been central to the few authors in the field of disability who have captured parents' accounts of their experiences of caring for their disabled child.

These authors have noted that the birth or diagnosis of a child with an impairment is seldom accompanied by social or cultural markers that publicly acknowledge motherhood (congratulations, admiration of the infant, gifts and celebrations after the birth of the child, etc.), which is perceived by many mothers of disabled children as reducing motherhood to something lesser, shameful, "other," or different, from "real" motherhood [17]. This lack of acknowledgement of the birth of a disabled infant was perceived by some parents as negating the existence of their child: "When she was born and people heard there was something wrong, like, the congratulations disappear. You don't get any of that. It's like you don't have a baby [17]." The loss of symbolic capital associated with their sudden entrance into a stigmatized social category is eloquently articulated by one mother of a premature infant: "And ...I realized how much I missed out on having my first baby. Having the family come in to see her, to see the child...All the rituals. I missed out on showers. I missed out on everything. There was nothing that was pleasure about her birth, and even after her birth. You know, you don't send out announcements, because what's there to announce? That you had a one-pound-five-ounce baby, you know? It's all those rituals. They shouldn't mean anything, but they do."

Insider or outsider?

...[there were] little insider/outsider moments in the process for all of us (me and Angie on [choice of] photographic paper), Leslie and you on other things... Garth [designer] and Angie... The parents and Angie against the academics...

–Kathleen

Angela describes herself as an insider and tells the story of how she came to photograph her child:

It came about at a time in my creative career when I actually did not have a profession any more. I was mothering Nikki and I was pregnant with Christine but I had the good fortune to be on a cultural exchange programme and I had a master class with a well known photographer from Finland. We had it here in my studio and it was twelve years since I had been a student. The theme that he set for us was to work on a personal confrontation. That was a moment when the lights just went on! It had been lying dormant in my brain for a while and it was just so clear that I had to work on my confrontation with Nikki. It was at a time when Nikki was going through all these medical investigations so it was a perfect device to utilise and I wanted to photograph the duality.

All the social scientists in the team felt that they had great respect for Angela's insider status, and sympathized with her personal investment in the project and also found it difficult to disagree with her because of her insider associated vulnerability. Leslie comments:

It is not easy being the mother of this child. In the theory you work with an insider and that is great, we have participation – that is what

disability studies say – but in reality that is terribly complicated, because then: whose voice is right! This is something which is so close to her. It is hard saying to Angie "We disagree with you on this part of the book because then we disagree with your soul, because your soul is in this book". It feels like part of mine is too, but less so, though it is still personal.

There are different memories from team members about delays in the project and the complicated process of its completion. Once again, these memories are predicated in different, but very personal, investments in a team process. Amelia describes a meeting where the publishers threatened to pull out of the project:

...it was so close to her that I think she may have lost perspective at times... We had one awful meeting where she wanted things to change the quality of the book or layout again, I can't remember, and our editor eventually said "we're out!". This was towards the end! That was the time that I could see Leslie was at his most anxious. It was terrible. At times I felt she was just so close and it was too sore for her.

Leslie shares this memory, but Angela's memory of events is different – she thought delays were due to pressures of other work at the HSRC. It is less important to judge which of these stories is "correct" than to acknowledge how different they are.

Although Angela spoke of the power differential between the social scientists and herself during her interview, our status as "outsiders" in the world of disability was disempowering for us. We were acutely aware of Angela's role as the mother of a disabled child, which, at an emotional level, we believed gave her ownership or expert rights we felt we had not earned. These rights combined with her insider-associated vulnerability meant that, for example, there were some lengthy negotiations around quality of presentation and interpretation of images, which may not have taken place otherwise. Angela herself describes being "indulged" at times:

I felt very supported by Leslie and Kathleen. I felt quite indulged in fact. It was fabulous... I loved the way they spoke about it (photographs).

As we can see, there was a complex interplay of power dynamics within the team, which shifted according to what topic or area of expertise was under discussion. Who was the insider, outsider or expert at any given moment was fluid and depended on their knowledge, experience and role in relation to other members of the team. This relational definition of understanding the self is described by Amelia:

We learned a lot about the "us and them" debate by being academics collaborating with, not only an artist, but the mother of a disabled child...I have come to believe very much that for any of us who think we are able bodied, it actually is temporary for all of us, we get ill, we get injured, and really that othering process, the truth is that the product of who we are is always relational. By othering anyone, or making them different is a way of making us feel better about ourselves, and it is false.

Kathleen adds:

...this experience of being relational in terms of professional expertise was very challenging and also very productive. I certainly felt

a kind of room to connect spheres that was new for me, and that was productive in terms of what I felt confident in doing in later work. This insider/outsiderness echoes something we tried to write about in the book and that Angie made images of: that parents of disabled children are constantly trying to mediate what they see as their children's experience of being outsiders – sometimes in ways that support the stigma, sometimes through trying to get diagnoses, sometimes in ways that make new spaces for their children where they are not stigmatised, and sometimes in an attempt to mediate what is really their own experience as parents that they are stigmatised, and made to feel outsiders.

Conclusion

I am becoming more interested in doing interdisciplinary work and incorporating different ways of seeing the world. I now want to do different things that will put me in touch with people who see the world differently to me. I find that exciting. This book has helped me, so it is a resounding yes. Will I do it again? Yes. I will be better at handling the frustrations. I started out being too intolerant. Now I see we don't have right and wrong ways, we just have ways in which we are personally invested.

– Amelia

One of the most profound lessons learnt from interdisciplinary collaboration of this kind is watching our discomfort when our boundaries – the structures from which we draw our professional identities – are prodded and tested. Through this process, we have all learnt to transition through the uncomfortable no-mans-land between disciplinary or professional boundaries to meet each other on the rare occasion we abandon our defences and we are open to another conceptual world. In these moments, we are able to receive new knowledge, new experiences and integrate them with our own, resulting a vastly richer understanding.

We hope that we will learn to generalize this knowledge to other similar situations, because it applies to many. Us and them categorization permeates our thinking. It characterizes some of the most simplistic thinking in the world of disability – able-bodied vs. disabled. In reality, there are no such categories, we all reside along a highly differentiated continuum of changing states of impairment and health. If we open ourselves up to this reality, we can meet each other and draw on each other's knowledge and experience.

In those moments where we are open enough to allow our conceptual worlds to collide and connect meaningfully with others, we open ourselves up to discover something closer to truth; at the very least, a multi-dimensional reality; an expanded awareness. In Angela's words:

I could start tomorrow again to do it. Because that inspires me. That's what creative souls need, that's what feeds us.

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