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3 Inclusive research: Stories from the field

In a book about the nature of a particular kind of research there is a strong role for examples that illustrate ideas in action. Chapters 1 and 2 indicate the diversity of concepts and evolving practices encompassed within inclusive research approaches. In this chapter, I illustrate some of the ways that inclusive research is practised. To organize the examples in a simplified way I use the framework of:

1. examples of research led by lay researchers/user groups,
2. examples of research conducted in partnership between academics and lay researchers/user groups,
3. examples of research by academics designed to enhance the active participation of participants/user groups.

I deliberately include examples from different fields and disciplines and select those that give the reader insights into the researchers' thinking as well as actions. I end the chapter with some thoughts about how the skills of inclusive research are taught and learned.

Lay researcher-led research

As I have discussed, for some, lay researcher-led research is the pinnacle of inclusive research. In this section, I present examples that illustrate the diversity of research that can be termed lay-researcher led. This diversity encompasses rationales, types of research and the methods used. I have subdivided this section into three examples of research projects that challenge the system, one example of self-advocacy research, and a section describing and discussing child-led research.

User-led research challenging the system

My first set of examples comes from groups using (or resisting) services, as these often engage in research that challenges those services or that

reflects a fundamentally different perspective. To illustrate this point I present three projects here, focusing on their *raison d'être*: one led by psychiatric system survivors, one led by women survivors of alcohol misuse and one led by a community group for people who are LGBT.

Research by psychiatric system survivors can be driven by revulsion at traditional research done *on* them, which they experience as invasive and exploitative (Beresford and Wallcraft, 1997). Understandably, projects like the National User Involvement Project (Lindlow, 1996, cited by Beresford and Wallcraft, 1997) represent a resistance to being researched by people holding power over them. Beresford and Wallcraft (1997, p. 801) explain:

Sharp differences between survivor-led research and that carried out by mental health professionals are often revealed in the choice of starting point, subject matter and perspective. While psychiatric researchers generally evaluate existing orthodox psychiatric interventions from an assumption that mental illness can be clinically defined, survivor-led research often treats the concept of mental illness as open to question. While the findings of orthodox research generally point to incremental changes within the existing paradigm, user-led research posits more radical shifts of control, rights, knowledge and resources to service users and their organizations.

The different starting point is evident in Staddon's (2012) emancipatory research with women survivors of alcohol issues and their treatment, which was planned with other women in the same position as her. She was, she explains, 'very aware already that our ways of seeing were quite different from those of the so-called experts in the field' (p. 195). She reflects on how the women were put in touch with each other through focus groups, and how: 'If I had not been a service user, as well as a researcher, if the research Advisory Group had not been made up of service users – perhaps nothing more would have come from these meetings. But the pain and anger of these women resonated with us all' (p. 196). The research experience led to the women continuing to meet as a regular network and, greatly influenced by the social model of disability, to theorize afresh and develop a social model of alcohol 'misuse' focused on social components and recognizing the blame culture in services. The 'core component' of the group 'was the refusal to judge or be judged, and to challenge morally and medically informed critiques of their lives' (p. 199).

Count Me in Too, the LGBT community-led project (Browne et al., 2012), involved partnership working from the beginning stage of designing the research, setting out to 'empower marginalized LGBT people, and yet still contribute to the agendas of those "in power"' (p. 205). The PAR approach 'meant contesting traditional divides between community, university and the public sector' (p. 207) with key stakeholders working together 'to generate useful data, crossing and blurring boundaries between activism, service provision, researcher, community member, LGBT, cisgendered [i.e. 'those whose gender assignment at birth continues to be the gender that they identify with and live with'], heterosexual etc' (pp. 208–9). Browne et al. (2012) reflect on the importance of marginalized people sitting down together with powerful people to effect social change. It was this, rather than the mix of research methods they adopted, that made their research powerful.

User-led research: The history of self-advocacy

These examples are very telling regarding what was valued about the research by those involved in conducting it – the *why* – yet they tell very little about the detail of the *how* – what conducting the research inclusively involved. I now turn, therefore, to a more detailed example of research led by lay people who are usually the focus of other people's research. The research was conducted by members of Central England People First (CEPF), a self-advocacy group of people with learning disabilities that has been together for 21 years, with experience of several research projects. The particular study was of the history of self-advocacy focusing on the CEPF group in particular, motivated by their desire to consider and celebrate their journey as individuals and together, especially in light of an apparent decline in self-advocacy groups and members. The paper reporting the research is in the public domain (Walmsley and CEPF, in press) and group members also spoke about their research in the *Doing Research Inclusively, Doing Research Well?* study in which inclusive researchers came together to explore quality in inclusive research (Nind and Vinha, 2012, 2013).

Walmsley spells out exactly who led the history of self-advocacy research:

This was an inclusive research project. It met all the criteria for inclusive research set by Walmsley and Johnson (2003). Members

of CEPF actively chose to do the project, were in charge of key decisions and carried out much of the work. It was a team approach. Non disabled people played a hugely significant role, as supporters, advisors and expert consultants – it could not have happened without them – but decisions remained in the hands of the CEPF project team. In this sense it demonstrates the viability of an inclusive research approach to a substantial project. (Walmsley and CEPF, in press)

The self-advocates reiterate their role as lead researchers: ‘CEPF has always made sure people with learning difficulties run things, so the project was led by one of our members, Craig Hart, supported by the Project Worker, and 7 CEPF members – Ian, Mark, Angela, Stephen, John, Philip and Louise.’ What is illuminative for our purposes in understanding the nature of inclusive research is that they are very explicit about who did what in the research process. This is something that Walmsley (2004), working with them on the research, has argued for as necessary to the credibility and sustainability of inclusive research. This transparency is further enhanced by their experimentation with using different fonts in the paper to indicate whose ideas are being voiced at any one time – who is speaking – though they acknowledge that the ownership of many key ideas was shared. The paper explains that, while the self-advocates recorded the history of their group, Walmsley – the academic – wrote the history of self-advocacy. The self-advocates explain that ‘this was because we have not read the books and papers that Jan Walmsley had read’. They expand further:

For professionals and other important people we need to influence we needed to write something that helped explain self advocacy. We knew that they might want more detail than would normally be in an easy read document. This was a difficult decision but we decided that with help we could write something that we couldn’t write by ourselves but that we could understand. (Walmsley and CEPF, in press)

Echoing all of the inclusive researchers participating in our reflective focus groups (Nind and Vinha, 2012), this group’s story of their research approach is one of compromises in which pragmatics are held in delicate balance with principled decisions. Unable to write the bigger story themselves, the group engaged a trusted academic researcher to do this part, thus showing

that research led by lay people does not have to be fully conducted by them. They tell the story of coming to the decision that they could not do the whole thing themselves and to bid for funds for a project worker with oral history skills to work with them as well as to buy in equipment and website expertise, and to fund a booklet, exhibition and workshops 'for our members to help them learn about archives, oral history, interviewing, website development, scanning, Skype, and writing up what we found' (Walmsley and CEPF, in press).

The study was funded by the Heritage Lottery Fund and the research was conducted while the group were at the same time working hard to seek other funds for their own organizational survival. The research methods included interviewing key people in the organization's history, building a photographic log and photo stories of the history of the group, and building a timeline of key events. Particular challenges arose around deciding the best response to the ethical dilemmas surrounding interpersonal troubles ('battles') in the group dynamic. Some, but not all of the interviewing was done by people with learning disabilities. This compromise was an originally unanticipated result of the sensitivities that transpired regarding interviewing people known to each other with shared pasts and not always enough distance between them for comfort (an experience similarly reported by Grant, 2013).

This study was research in which hearing, rather than seamlessly blending, the different voices was very important. The self-advocates explain:

We have always debated whether support workers should have their own voice, and on the whole we have said they shouldn't. We sorted this by doing an interview with the support worker and putting it on the website. We also included some of the things he thought were important in the Timeline and the booklet. So his voice is there too, alongside ours. That seemed fair. (Walmsley and CEPF, in press)

Experienced at understanding diverse needs they organized the booklet reporting the research so that, when open, one page was in the academic's words and the page alongside it was in the words of the self-advocates. The fact that not everything was fully accessible was also a compromise – the controversial nature of which the research team fully understood in a conscious decision, carefully deliberated: 'We were not keen to have things which were not in easy read, but we understand that sometimes

it is important to make exceptions to our rules' (Walmsley and CEPF, in press).

The findings from this research are testimony to the 'personal is political' fundamental premise. They show a history with periods of expansion and retraction as well as personal and group triumphs. The paper, which focuses on the research process as well as products, also demonstrates the power of doing the research for providing those involved with fresh insights into their past, their current situation and possible futures.

Child-led research

I now turn to examples of research led by less experienced but more formally trained researchers, that is, by children. The contrast between these and earlier examples serve to illuminate the diversity in research led by lay researchers. Kellett's (2005b) book codifying the process of developing children as researchers includes the training she takes children through at the Children's Research Centre and three accounts of research by children. These illustrate the traditional research processes the children underwent, as well as those missed such as reviewing the literature and locating the knowledge generated within the wider field. They show how the children's studies are inevitably motivated by their interests rather more than reflection on their life experiences and personal-political concerns evident in the research accounts of marginalized adults. Perhaps influenced by Kellett's strong view that adults should not interfere, they also lack the sense of combining the skills of individuals from different backgrounds. Thus, these appear to be a mix of school project and conventional research on a very small scale.

Paul O'Brien looked at how experience of death of a relative or pet affected children of his age at his school. This pupil (from Year 7) identified participants through a survey and then did short follow-up interviews with eight of them. Using processes taught through Kellett's approach he was careful to consider the ethics associated with talking about sensitive subjects. He reports the findings question by question and discusses the patterns and diversity he found among interviewees' responses, as well as what doing the research meant to him personally. Unlike the self-advocates discussed, he was a lone researcher and made no attempt to recruit others to do the parts of the research that were beyond his personal skills and the scale of his small, unfunded study, namely the literature review, contextual and theoretical parts.

Ben Davies and Selena Ryan-Vig researched together pupils' views about mixed-gender football, beginning with some analysis of the coverage of men's and women's football in the media and using web searching. Trained in research processes they report on their mixed methods approach comprising a local questionnaire and an experiment involving introducing the experience of mixed-gender football, with observations and follow-up interviews. The child researchers confidently refer to confounding variables and potential bias and discuss the rationale for their main decisions. They present their findings in tables indicating the outcomes of their basic descriptive quantitative analysis and proffer some plausible explanations for patterns in the data. Another duo, Anna Carlini and Emma Barry, report on researching the interactions of peers with school children who were small and looked younger than their chronological age. They did some thematic analysis and reflection on their findings and processes. These research reports by children do not quite portray the sense of them enjoying the emancipation or empowerment seen in other user-led accounts. Nonetheless, there is a strong message about new skills learned and confidence raised.

The various examples of lay researcher-led research highlight the ways in which leading research may involve lay people in challenging, or adopting, traditional research approaches. Lay researchers may recruit academics to do parts of the research or work alone. They may or may not change the way they see themselves and their situations, but they invariably develop new skills and confidence. The outcomes of their research are likely to be different from the outcomes had the research been led by academics.

Partnership research

Partnership research is less focused on who leads and more on how people work together. Sometimes those involved deliberately liberate themselves from constraints imposed by their identity labels. Some but not all partnership research is PAR, but I begin with a PAR example to show how an academic and a group of young women collaborated. This section contains illustrations of highly diverse approaches and methods, all of which can be termed partnership research. The examples of collaborative research projects share something with projects led by lay researchers – the challenge for everyone involved to work out what compromises are acceptable to them. They also illustrate the challenges

surrounding who has expertise and ownership, and how to function in unfamiliar roles and unfamiliar relationships. They introduce new terms that are emerging for those roles. ‘Learner researchers’, ‘volunteers’ and ‘co-learners’ emerge as terms alongside ‘co-researchers’. Ultimately, this section presents examples of research alliances formed in diverse ways but for a shared purpose of doing research to facilitate changes in people’s life situations.

The Makes Me Mad project – an example of deep participatory research

The Makes Me Mad project is interesting because it has the strong political, transformative dimension often associated with user-led research, but without being conducted independently of academic influence. The account is provided by the academic involved and the women’s voices are heard through this filter, rather than this being a story jointly told. Cahill (2007) provides a rich example of PAR with young women (aged 16 to 22) in New York, which she describes as deeply participatory, collaborative and reciprocal. They began their work together with an open agenda – the ‘everyday lives of young women in the city’ (p. 300); ownership of the project was discussed from its inception and the study evolved organically: ‘After much deliberation and debate the young women decided to focus our research on the issue of stereotypical (mis)representations of young people of color and the relationship between these images and processes of financial disinvestment from their neighborhood. They entitled the project “Makes Me Mad: Stereotypes of Young Urban Womyn of Color”’ (Cahill, 2007, p. 300). Cahill set out to create what Torre (2005) had described as a ‘democratic space of radical inclusivity’. Like other inclusive researchers she was influenced by the ideas of Freire and she was highly focused on developing the co-researchers’ skills in multiple research methods, not least to help equalize power between them all. She worked to create space for dialogue, which involved ‘actively facilitating everyone’s involvement’, ‘interrupting silences’ and ‘disrupting dominant voices’, as well as modelling being an active listener (Cahill, 2007, p. 302). But she is clear that her role transcended being a passive facilitator of others’ participation; she was a collaborator, also involved in the research, and also holding opinions. She reflects, ‘The key issue however, if one is to participate in ways that do not silence others, is to be very careful about the grounds on which you make a contribution. When I did disagree, I made sure to first

clarify I was speaking from my own experience and standpoint, without making any claim to authority' (p. 302).

Cahill (2007) performed a role noticeably absent in the children's independent research discussed earlier, but offered by the academic researcher consulted by CEPF. She supported her co-researchers in making 'connections between participant's interpretations and social and political theory'; she observes, however, that the 'co-researchers soon began to play this role for each other', thereby 'through this process we collectively developed theory' (pp. 302–3). The account of the project makes some of this process explicit. They began with agreeing rules of engagement that enabled them to 'constructively address differences not just consensus' (p. 303). They developed methodological collaborative 'rituals' to support their production of group-owned knowledge (p. 303). After Lather's (1986) 'research as praxis', Cahill refers to their practice as a 'collective praxis approach' (p. 303). Cahill did not opt for the visual methodologies frequently used in participatory research with children and young people to increase engagement and address variation in competence with language and literacy; instead, the group's methods centred on written and verbal expression and the idea of writing as praxis. As well as private journal writing the co-researchers spent time in dialogue and 'note-taking on "our wall"', which produced a 'public memory of shared knowledge production' (p. 303).

I have argued elsewhere that the analysis stage is often the least developed or explicitly discussed in inclusive research, but most developed and inclusive perhaps when 'embedded and boundary-less – part of a broader approach to participation and to acting responsibly' (Nind, 2011, p. 358). I have since learned of many more examples of this and Cahill describes it in their project:

Moments of analysis emerged organically at multiple and regular points as part of our reflective praxis rather than being a set 'phase' of research. Analysis also fed directly back into our project as part of a looped process of critical reflection. Crucially therefore, the analysis process was not external to the process but an integral part of it in which all the co-researchers participated and learned. (2007, p. 306)

She goes on to consider their processes of actively listening to each other's perspectives and making sense of these as representing a kind of participatory grounded theory 'with the women building an understanding

of themselves as they study themselves' (p. 306). She also reports how some aspects of academic research, like intensive collaborative coding, did become points of contention when the co-researchers were not convinced that they were worthwhile.

Researching our lives – an example of participatory data analysis

The previous example is helpful in including an account of the data analysis process as integral to the PAR. I include this next example of partnership research because it is particularly expansive regarding the shared approach to data analysis in which the voice-centred relational method was used. Moreover, it helpfully highlights questions of whether there is an expert in inclusive research conducted collaboratively, or whether this expert role is shared or passed around. In particular it shows how, regardless of the best intentions and careful research methods of the academic researchers, they can still inadvertently dominate decisions about the selection of focus. It also tells of the high levels of sustained commitment to the task and to each other demanded by research involving working together across the stages of research.

Byrne et al. (2009) describe a study involving socio-economically disadvantaged teenagers in Ireland who had left school at the earliest opportunity. The academics engaged in research with a participatory ethos in a team with the teenagers and an artist who they engaged to help them 'to reflect on and research themselves' (p. 70) using film, music and painting. As is so often the case in inclusive research, 'much time was spent clarifying the expectations of all members of the research team in terms of project process, practices and outcomes' (p. 70). Also in common with other inclusive research projects there was an agenda that included learning new skills and potentially leading to wider change – in this case, change in the school system.

Inclusive researchers struggle with voice and language. One challenge is deciding on the term to describe those involved, for which there is no commonly agreed vocabulary. In this study the teenagers are referred to, not as co-researchers, but as 'learner researchers' (p. 71). Another challenge is about how to manage – include and balance – the different voices involved. Byrne et al. (2009, p. 70) selected the voice-centred relational method because it 'offered the possibility of participatory meaning making that emphasized the voices and interests of research participants'. They

saw this as a means for analysing interview transcripts collaboratively that would require everyone involved 'to listen attentively to the voice relating the story' (p. 68), to confront difference, and to identify and make the conventions of interpretation explicit. The researchers, including the 'learner researchers', worked on the transcripts methodically and painstakingly in teams and pairs to correct inaccuracies, fill gaps and add to the narrative, persisting despite the 'difficult, tedious and time consuming' (p. 74) nature of the analysis work. Byrne et al. (2009) tell of how at first the academics neglected to see themselves (with their privileged lives) as narrators and as the researched: 'Throughout the project the teenagers had demonstrated that they could be researchers; the academics on the other hand found it difficult to become the researched and step out of the role of expert researcher' (p. 75).

The study of falls – collaborative research with older people

There are many more examples in the literature of inclusive research with young people than older people and I include the next example in part to counter this as well as to show how partnerships can be multidimensional and valued by funders. Ross et al. (2005) reflect on their partnership involving the academic disciplines of nursing, gerontology and geriatrics, with local health and social care providers and the community health council – the 'consumers'. They joined forces to explore the views of older people, carers, and health and social care professionals on the risk of older people falling. Consumer involvement was a condition of their Department of Health funding and they could access support and training from EQUIP (Effectiveness and Quality in User Involvement Projects) who were specialists in this. They formed a consumer panel of 21 members with diverse experience and concerns and who provided links with other local organizations; this panel worked 'alongside the research team as partners' (p. 270). 'Panel meetings were chaired by the consumer member of the research team. This was important since it helped to establish the panel's identity as a group of consumers separate from, but working alongside, the research team' (p. 271). They needed to be clear that this was worthwhile and not "'just another talking shop'" (p. 274). Consumers were involved in project design, management, analysis and dissemination stages. Ross et al. note the importance of openness in the early stages in which 'it was evident that participants were beginning to set the agenda for the

consumer panel, and that panel meetings would need to be flexible to take into account panel members' concerns which were not strictly within the project's remit' (p. 271). Similar to an advisory group, the panel worked to ensure relevance for older people, but they also discussed research methods and got involved with data analysis.

This project is distinctive as an example of collaboration in research not just because of the consumer panel, but because of the role of the research nurse who, in recognition of the challenges in involving older people, eased the development of relationships through careful communication between panel members and between meetings. The research nurse also collated and analysed data from the panel. These data indicated their positive feelings about being involved, not just for their own benefit but in terms of shaping the effectiveness of the recruitment and methods, steering the team away from overprotection and towards speaking appropriately and listening intently. In common with other inclusive researchers, the group found that the role of communication and time to develop research relationships were crucial. Usefully, Ross et al. (2005, p. 273) provide examples of the ways in which older people on the consumer panel made the research participatory, such as one member acting as an independent observer in focus groups and feeding back on 'the appropriateness and consistency of method, facilitation approach, and equity of participation of focus group members'. In another example, the panel joined the researchers in preliminary analysis of interview data to develop a vignette for use in interviews with health and social care professionals.

Collaborative life histories – partnership research in the context of a doctoral thesis

The next example illustrates how research partnerships can be asymmetric in other ways. Here a doctoral researcher, collaborating with young adults with learning disabilities in Iceland, sheds further light on the ways in which expertise and analysis may be tackled in inclusive research collaborations. The account of the research (Bjornsdottir and Svendsdottir, 2008) is co-written by the doctoral researcher and one of the young adults involved. They are explicit about how, in co-writing, they spent time in preparation, recording meetings, 'then separately we wrote down our reflections and finally Kristin incorporated all of these into this paper and put our thoughts into context with other writings on the subject of inclusive research. In this paper we want to present a joint voice, which is

a product of our collaboration' (p. 265). The concept of joint ideas, if not joint voice, is held in common with the processes and research report by Walmsley and CEPF (in press), but in this case without the people with learning disabilities being in charge. The realities of joint voice, authority and authorship are ones that researchers with learning disabilities and their allies often struggle with (McClimens, 2008).

The research of Bjornsdottir and Svendsdottir (2008) comprises the life histories of adults with learning disabilities. They explain the interdependency we have seen in other examples: 'We have done some analysis together; mostly through discussions. Kristin's role is then to place Aileen's story with the other stories into historical and theoretical context' (p. 265). They also reflect on the question of ownership of the research, clarifying that the 'collaborators' (as opposed to co-researchers or learner researchers, the terms used in examples so far) own their own life stories, but Kristin owns her doctoral dissertation. In this complex set of research relationships Kristin is an advocate for disabled people, an ally and, as Shakespeare (1996) suggests, even as a non-disabled person, someone with a stake in disability. Aileen and one of the other people among the six sharing their life stories wanted to be involved in the whole research process. While ultimately Aileen co-authored one part of the dissertation through the inclusion of the paper within it, the product of the research, the ideas and the terminology were not fully accessible. Another non-collaborative element, or compromise in inclusive research terms, was that the people with learning disabilities were not involved in choosing the theoretical framework. Bjornsdottir and Svendsdottir (2008, p. 266) reflect: 'We have compared our collaboration with the five criteria of inclusive research set forth by Walmsley and Johnson (2003) and have come to the conclusion that doctoral projects such as this one can most likely never be fully inclusive.'

I include this example, nonetheless, as it illustrates the range of collaborative arrangements and the kinds of study at the edges of partnership research. The politics of inclusive research are still present. People like Aileen sharing life stories are motivated by a desire to prevent repetition of bad things happening and to influence practice. As Bjornsdottir and Svendsdottir (2008, p. 266) reflect, Aileen's 'role as a co-researcher and self-advocate are interwoven and driven by the need to be heard (Goodley 2000)'. Less like the examples of the individualized and relatively dispassionate child-led research, and more like PAR, there is a group social responsibility at work here.

Bjornsdottir and Svendsdottir (2008) give careful consideration to the question of whether Aileen's involvement in the research was empowering, concluding that seeing the research as the thing that empowered her 'would be an oversimplification of Aileen's life' (p. 266). Nevertheless, they are clear that they 'do not reject the idea of empowerment through research' and that 'we agree that the collaboration has been enjoyable and empowering for both of us' (p. 266). They tell of how spending time together in the research brought them closer and affected the power dynamic between them. They learned how much they had in common, which made the differences between them less of a preoccupation. This is a sentiment echoed by the inclusive researchers with and without a label of learning disability that shared in dialogue in *Doing Research Inclusively, Doing Research Well?* (Nind and Vinha, 2012).

The use and generation of theory by inclusive researchers is interesting and one of the focuses for reflection and dialogue among inclusive researchers in the learning disability field (Nind and Vinha, 2012). Bjornsdottir and Svendsdottir (2008) use Bourdieu's (1984) theory of social capital to explore a conundrum. People with learning disabilities, they argue, have little cultural capital in the field of disability studies where there is a need to use scholarly language to compete for power and 'maximise profit by following the rules set by the dominant group' (p. 268). Simultaneously, non-disabled supporters/allies also lack capital in the field of disability studies by dint of not being disabled. They therefore see writing the academic paper as a collaboration in which they are 'gambling for capital'.

Gay and Grey – PAR in the context of a complex collaboration

The Gay and Grey project is another complex collaboration in research, this time a 'joint initiative between a voluntary agency working with older people' and a university (Fenge, 2010, pp. 881–2). It shows how people can work together across difference for common (and some individual) good. The research, funded by the Big Lottery, was aimed at identifying factors and issues contributing towards the exclusion of gay people from the wider community of older people and from support services, and at identifying how to address these to promote greater social inclusion. Fenge (2010) argues that the collaborative approach was born from a context of increasing policy and practice emphasis on working in partnership. It was motivated by a desire to get unheard voices heard, to be anti-oppressive and to value diversity. The university and voluntary agency partners chose

PAR as their approach as they were not older/lesbians themselves and they were acutely aware, therefore, of their problematic status as outsiders. They addressed this by recruiting 'volunteer' insiders, thereby securing user involvement for the pilot work and at the stage of securing funding. Once the volunteers were recruited they were able to negotiate the aims of the project and a commitment to participatory approach.

While Fenge, the academic, has written about the process and the politics of the inclusive research, many of the products of this research that relate to the substantive findings are collaboratively written with the 'volunteers' (another new term to describe the lay people involved) who were active in dissemination as they were in all stages of the work. Fenge (2010) reflects on the principles (from Whitmore and McGee, 2001, p. 396) that governed their way of working together: non-intrusive collaboration, mutual trust and respect, solidarity, mutuality and equality, a focus on process, and language as an expression of culture and power. She is honest about the volunteers having different aims and motivations from the university and voluntary agency partners, but she recognizes that this is usual in PAR. The 'outsider' researchers were more pressured by the funder requirements and the volunteers were keener to rush to action. She also relates some of the divisions of labour that arose, with women ending up leading the research part and men doing the outreach work; she regrets that without people from minority ethnic communities being involved there was still an element of silencing of some. Interestingly, we see that among the different aspirations and roles of the volunteers, and with some ebb and flow of personnel, a small group emerged as the most comfortable with mutual learning and became what Fenge (2010, p. 886) refers to as 'co-learners' – those with whom there was a strong feeling of solidarity and long-lived collaboration. For Fenge (2010), crucial elements in the success of this inclusive research were the central role played by dialogue and the time needed for trust to develop (for which the funding to permit this was essential). The pattern that emerges repeatedly is that inclusive research takes time, and the additional time is not just for the business of making the relationships work (Byrne et al., 2009; Nind and Vinha, 2012; Lewis and MacLeod, in press).

Hearing (our) voices – PAR in a contrasting context

Another example of inclusive research using the PAR approach, a collaboration between an academic and lay people diagnosed with schizophrenia,

comes from Calgary, Canada and is narrated in detail by Schneider (2010) (the draft having been considered by the wider group). This example is useful because of the detail and the passion in the account. Schneider and the *Unsung Heroes* Peer Support Group undertook two pieces of inclusive research together: one small project about communication between people diagnosed with schizophrenia and their medical professionals, and one larger research project about housing for people diagnosed with schizophrenia. The first project was prompted by a funding call that led to the academic making contact with the group and their developing a proposal together. The second project arose from concerns raised by group members as well as a desire to do further research. In both cases the academic (who was also the mother of a young adult with schizophrenia) was instrumental in seeing the funding opportunities, but these were not studies led by the academic or the support group: they were studies planned, conducted and disseminated together. As Schneider (2010, pp. 31–2) sums up:

Our projects fall somewhere between collaboration and control. I initiated the first project, but the research group members initiated the second and in both projects they had a significant degree of control over decision-making in all aspects of the research and dissemination. I became the facilitator, trainer, and supporter rather than the expert researcher, providing the information they needed to make decisions, but not making the decisions for them. . . . We negotiated ways to accomplish their goals without compromising the progress of the research.

The dissemination included a co-written academic paper, theatre productions, documentary film and poster book.

In introducing the book about the research Schneider (2010, pp. 13–14) stresses features of PAR that were important to them: democratic process, co-operative inquiry with co-researchers, using the expertise of lived experience, transforming ‘the social relations of research by regarding participants as both co-researchers and co-subjects’, with ‘an emancipatory or empowerment agenda’. She argues that ‘as participatory research is fundamentally about “the right to speak” it offers people diagnosed with schizophrenia a way to both reclaim a positive identity and make a contribution to society’ (p. 35). These ideas and premises are recurrent themes throughout this book. The research, drawing on Fisher (1984), adds the

dimension of narrative as a way of knowing and as a basis of community. This element of sharing stories and ultimately creating a common story is implicit rather than explicit in many of the accounts of inclusive research. It is important as a means for validating different voices, narratives and narrators.

Schneider (2010) is an advocate for many of the ideas included in Chapter 2 as the drivers and influences on the evolution of inclusive research practices. For example, she makes the case for the useful, unique and superior knowledge that inclusive research can generate:

Inclusion of people diagnosed with schizophrenia in all aspects of knowledge production about schizophrenia, that is, in research, has the potential to produce knowledge that is not available in any other way. People with schizophrenia themselves know best about their experiences and what helps them to cope with these experiences. They are able to steer the research to the issues and concerns that are most important to them. Focusing the research in this way has the potential to provide information that can dramatically improve the care that people diagnosed with schizophrenia receive. (p. 25)

The claims she makes are tempered by phrasing about 'potential', indicating that these advantages are possible rather than automatic. Nonetheless, while these kinds of claims are harder to see in practice in some domains, they are evidenced in Schneider's (2010) book. One thing that helped in the democratization of expertise was that, as the academic, she was not an expert in mental health and so may have felt less the temptation for her knowledge to trump that of the co-researchers; instead, the necessary expertise was held very much among themselves as a team. Another claim relates to the aspiration for inclusive research to 'give voice' to marginalized people. Schneider (2010) is not alone in making the case for this and also in grappling with the dynamic of not being bossy or dominating (see Nind and Vinha, 2012). The research findings, though, testify to the value of partnership in decision making achieved through 'open and collegial communication' (p. 25) and to the impact benefits of public voice achieved through active involvement in dissemination.

An issue for inclusive research is that it is often set up to perform multiple roles in multiple ways. A key concern that has arisen for me in researching inclusive research is whether we ask too much of it (Nind and Vinha, 2012, 2013). For example, the research is meant to produce valid,

even superior knowledge, and at the same time produce tangible training, networking, social and employment benefits for those involved. Schneider (2010, p. 26) considers this and concludes that ‘the benefits we experienced [particularly overcoming isolation and gaining a sense of connection] are as important as the knowledge we produced, although they are a welcome by-product rather than a direct goal of the projects’. This position may reflect her role as narrator of the research story and her preoccupations as an academic researcher and grant-holder. Nonetheless, the range of benefits and their power emerge strongly from her account.

Academic-led research

Some argue that academic-led research, by its very nature, cannot be termed inclusive research in any meaningful sense. However, academic-led research includes rich accounts of how an inclusive research process may work in practice. MacLeod et al. (2013) comment that the detail of participatory methods is more often underreported, making it difficult to know what it is that researchers do that effectively enhances the active participation of their participants in parts or the whole of the process. These more transparent accounts, therefore, are all the more valuable.

The use of participatory methods in qualitative research – giving children choice

I begin the section on academic-led research with an example that epitomizes the kinds of moves that academics make to be participatory. Many academic researchers design their studies, or at least their methods, to maximize the active engagement of participants. This may be considered participatory research or research using participatory methods. The extent to which it is inclusive research, or differs from other forms of qualitative research, is contested (see Chapter 4). It is important to examine the dynamic between the researcher and the researched, who do not become merged or transformed in this kind of inclusive research but do come closer together with potential for reciprocity. Much of this research is with children and young people. Thomas and O’Kane (1998) discuss the process of their research about children’s participation in decision making when they are looked after by local authorities. They initially designed their research and set their objectives then began setting about maximizing the participation of their child participants. They explain: ‘we would claim

that the conduct of the research was participatory in a stronger sense than merely that it employed “user-friendly” materials; children were involved not only in choosing how they participated personally but in consciously influencing the direction of the research and in making decisions about its dissemination’ (p. 341). This concept of children choosing is fundamental to their approach, providing children with a choice of activities which included answering questions among other flexible and creative options. Thus children could opt to be involved in techniques that were more or less verbal or visual in orientation, and adapted to their individual preferences.

Thomas and O’Kane (1998) were acting on their view of the social child as agent and drawing ideas from life story work/PRA to offer data collection activities such as timelines, ‘my favourite place’, and ‘what I would change with my magic wand’ (p. 343). Their desire for children to have an active role in the research included a concern with the analysis stages. The first part of this involved the children being able to ‘choose subjects for discussion and decide what they wanted to say about them’ and extended into following ‘their understanding of questions and concepts as well as ours’ (p. 345). Secondly, there was an element of returning to the children more than once to provide the opportunity for them to review and refine their data. Thirdly, they describe ‘using group processes’ thereby creating ‘space where children could collectively reinterpret the research questions and do further work on the material brought from the individual interviews’ (p. 345). They thus ended up with a strong sense of the co-construction of knowledge:

Finally, at the conclusion of the research we worked with a group of eight volunteers from among the 47 children to make an audiotape of children’s comments from the research. This involved the group in helping to select and edit the comments in order to get across the messages which we and they agreed should be taken from the research. Throughout this process our own understanding of what were the important questions and the critical evidence concerning children’s participation in decisions developed reflexively with the children’s successive contributions to the research process. In the end it is hard to disentangle what was our contribution and what was theirs; but there is no doubt that the course followed by the research, and the final conclusions, were very different as a result of the children’s own interpretations of the data. (p. 345)

Choice and voice – when anything other than academic-led research seems impossible

Some contexts allow choice even when they do not lend themselves to partnership or lay researcher-led research. For example, Conolly (2008, p. 208) found that the 'full' participatory research she aspired to in her research with excluded school girls was unfeasible as their own difficult lives presented barriers to them bringing the commitment and ethical care needed. Nonetheless, Conolly still wanted them to enjoy 'some ownership of the research process', and so she adopted 'the middle ground' of 'seeking to understand their lives and what was important to them' by using 'the reflexive co-construction of biographies through task-based interviewing' (p. 208). This involved plenty of choice and an exchange of information as she herself joined in the process of sharing.

In a similar action-oriented study, colleagues and I engaged with girls excluded from mainstream school and their new special school staff and we looked to give the girls choice from a range of verbal and visual methods (Clarke et al., 2011). The research was aimed at developing an evidence-based holistic curriculum model for girls with behavioural, social and emotional difficulties. How the girls experienced various curricula and schools was as important to us as the academic evidence. We were acutely aware that, for such girls who contravene social and gender norms and become marginalized in their social status, the opportunities to have their voices heard and views trusted are sparse; there is no self-advocacy movement among troubled youngsters and individual attempts to speak out are interpreted through the lens of the young person being troublesome. We were also aware, as Charmaz (2008, p. 14) powerfully argues, that being on the margins 'offers fresh interpretations of the centre, and may open possibilities for renewal, change and transformation'. While we appreciated Greene's (2009) warning that being asked to participate in research activities can feel like yet another adult-initiated chore, we were also convinced by Holland et al.'s (2008) argument that we could avoid this adult-centredness by enabling young people to choose how they communicated with us. Policy shifts towards hearing pupils' voices had led to somewhat superficial processes around this so we expected the girls were likely to be cynical unless we offered genuine choices. We did not perceive a simple process of giving the girls voice but, rather, influenced by Alcott's (1992) *The Problem of Speaking for Others*, sought to engage with the girls' voices, sensitive to our own privileged position and to the

socio-political context. We were not seeking to silence ourselves or others, but to facilitate imaginative listening (Corbett, 1998) and transformative dialogue (Fielding, 2004).

The operationalization of our aspirations and critically nuanced understandings of voice involved enabling the girls to draw on their preferences and competences as communicators. It also involved us developing our capacity as listeners. We sought to establish that we were all taking risks, within some safe boundaries, and that we were creating spaces for meaningful communication. This was not in the shape of anything the girls might interpret as counselling or imposing; rather, we offered opportunities to use the range of digital media available in the school's strongly visual environment. This extended to the consent process in which some of the girls helped to develop comic-strip style information sheets, developing their understanding of the issues while personalizing them and making them visual.

There was one particular method among an array offered that the girls took real ownership of – the video diary. The diary room, partly attractive because of the television series *Big Brother*, became a space they customized and made good use of. It suited them, with some girls going in independently and spontaneously to speak to camera and some preferring to speak with adults present or to be called to talk about a specific topic. In the diary room they felt safe and supported to reflect and did so readily, providing graphic accounts of school experiences in which their voices had not been sought or heard and of sense of disconnection from school. Their narratives highlighted the importance to them of student-centred systems for listening at the heart of the curriculum to represent that staff are open and care.

This project, while far from being participatory throughout the design and whole process, genuinely valued the girls' participation as active co-constructors of an understanding of how the curriculum should be designed. We found that 'the girls communicated openly, insightfully and, at times, at length with regard to a number of features relating to access to their schooling' (Clarke et al., 2011, p. 776). The option to participate as they wished enabled this to happen; furthermore, it facilitated the girls being viewed differently by the staff and by themselves. This did little to disrupt the asymmetric power relations of schooling, but it did disrupt some privileging and silencing of voices and it did generate worthwhile insights and fresh narratives.

Overcoming barriers to participation: Researching with adults on the autistic spectrum

Turning to a different participant group, academics have sought to overcome barriers to the participation in research of young adults on the autistic spectrum by working with the participants themselves to address the barriers and effective methods. MacLeod et al. (2013) argue that the social and communication difficulties of people with autism, and the perceptions of others around these, have a profound impact on their opportunities for inclusion in research. They observe that it is 'difficult and risky for "outsider" researchers to second guess the motivations and interpretations of individuals who may view the world very differently'. This is beginning to be corroborated, they suggest, by 'a small but growing body of evidence suggesting that research consulting directly with autistic participants can reveal findings to challenge current understandings' and that the insights generated show the value on more nuanced 'insider' perspectives. Yet the application of participatory approaches with individuals with autism is still very new and researchers are focusing on how this can be achieved.

MacLeod et al. (2013) reflect on their methodology in a study involving ten higher education students diagnosed as being on the autism spectrum, using interpretative phenomenological analysis to privilege the participants' expertise on their own experience. A pilot phase led to the identification of potential barriers to participation including participants' anxieties about the communication and interview process, time management challenges and potential for miscommunication. Again, providing choice for participants was the primary approach for addressing these and participants were able to choose between face-to-face, telephone or synchronous (real-time) online interview (although, against expectations, face-to-face was most preferred). Making the interview as predictable as possible was also important and participants were able to prepare in advance using a prompt sheet sent to them to help them identify significant events for educational success as a common frame of reference in interviews. There was also a comprehensive system of reminders that was valued by participants.

The research involved some negotiation around voice. A structured process of respondent validation involved transcript checking and dialogue about the researchers' initial analysis. The researchers were explicit that in the case of different interpretations both would be reported. Their findings illustrate the ways in which participants engaged with honesty and

commitment in the process of analysis. It was through these follow-up dialogues about the interpretation of data that 'the spaces between autistic and non-autistic interpretations could be explored and common ground identified' (MacLeod et al., 2013). The authors reflect on how much time was involved in conducting research that accommodated the needs of the autistic participants, which was possible given that they were working outside of the constraints of an externally funded project and timeline. They also reflect on the motivation of participants to be involved in research that might benefit others with autism (thus challenging notions of a lack of empathy being inherent to the condition). The research was perceived 'by its end-users as important and relevant to them' (MacLeod et al., 2013), perhaps to some extent as empowering for them. Seeing the research process from the participants' perspective is important and these researchers conclude that this means getting the balance of demands and commitment right for participants, rather than in accord with one's own assumptions or aspirations as researchers. Here they echo Bourke (2009), who observes that her participants did not always agree with the premise of 'the more participatory the better'.

An organic approach to involving children and young people

Next I contrast the more managed examples with some in which the nature of the participation evolves more organically. In the earlier examples the academic narrators are at pains to emphasize the ethical, flexible and responsive nature of their methodological approach, yet the children and young people were not able to shape the actual research questions. In their *(Extra)ordinary Lives* study, Holland et al. (2008) used an ethnographic approach to conduct research with children and young people and, simultaneously, to study their participatory research processes. In adopting this approach they limited the extent to which, as academic researchers, they predetermined their focus.

Holland et al. (2008, p. 11) regard some participatory research as 'more managed' compared to their 'less directive' and 'organic' approach. They used some formal participatory techniques, but found that these 'were less successful at generating data than more free-flowing, unplanned data generation techniques that mimicked more closely the young people's everyday means of communication' (p. 13). Moreover, they saw data analysis as integral rather than a separate stage and so their children and young

people were involved in analysis through their 'informal interactions seeking feedback'; this was ongoing rather than bounded. The authors reflect on how always sharing the emerging findings with the children and young people enhanced transparency but did not necessarily deepen understanding around those findings. From their experience they conclude:

We would argue that it is more important to pay close attention to *how* participation is enacted (at a range of levels, including participant-participant, participant-researchers, groups of participants-groups of workers, participants-end-users of research, including policy makers and academic audiences) than to focus in on *how much* participation was achieved. Meaningful exchanges, where individuals and groups have choices in what they wish to share, with whom and in what way, would seem to be at least as important as ensuring that participatory mechanisms are in place, such as advisory groups. Ticking participatory boxes, in civic participation practice or in research does not necessarily mean that participants experience the process as participatory, nor will it always affect the outcomes. (pp. 24–5)

Academics sometimes need to launch a project and allow this organic development for participation to grow.

Examples of academics engaging in dialogue

My next examples are important for the stress the researchers place on dialogue between themselves and participants. Participants may experience research in terms of being explicitly engaged in particular events or processes, or they may have the experience of being engaged in genuine dialogue with the academic researcher. This is one approach to increasing participants' agency in research that doctoral researchers whom I have supervised have made meaningful. Vinha (2011) made a conscious decision to make dialogue central to her research design about children's identities and experiences. This was rooted in the ideas of Freire (1967, 1970) and the idea of *conscientização*, that is, the act of ordinary or oppressed people coming to know the social, political and economic context of injustices and consequently taking action against the oppressive components of that given reality involving simultaneous reflection and action. Freire (1970, p. 27) was clear that any empowerment of oppressed people needed to be done by and for themselves. He asks, 'who are better prepared than the

oppressed to understand the terrible significance of an oppressed society? Who suffer the effects of oppression more than the oppressed? Who can better understand the necessity of liberation?' Freire regards dialogue as playing a key role in this empowerment as without it people's 'perception of themselves as oppressed is impaired by their submersion in the reality of oppression' (p. 27).

Vinha, in turn, set out to make the process of generating narrative through open-ended interviews into a dialogue, and to make it inclusive by adopting a radical position of solidarity with her participants. Her dialogical method of inquiry involved (1) listening to all voices, (2) 'a reflective process which embraces the praxis of naming the world collaboratively' and (3) methods to address power imbalances between the researcher and researched embedded in the social process. She worked with Freire's premises that dialogue requires humility, hope and critical thinking to develop the idea of a cyclical dialogic inquiry process. The starting point in this process is 'the researcher's humility and faith in the participants' capability to actively contribute to the research' and their 'openness to the participants as the basis of the dialogue' (Vinha, 2011, p. 86). There then follows a series of encounters, each involving an interview and follow-up consultation to hear each participant's own interpretation of what they have said and done so that sense-making is collaborative. Periods of reflection would then guide the next step in the interview-consultation-reflection cycle with the participant-researchers/ researcher-participants (the terminology Vinha chooses to reflect the duality of their roles).

Vinha (2011) also wanted to act on the concept of Clough and Barton (1998, p. 129) of turning up the volume on participants' (possibly timid) voices in her writing. Using narrative to organize experience also involved telling the dynamics as well as the content of the dialogue. To these ends she experimented with both verbal voice and visual voice as complementary to each other in the processes of forming the dialogue and telling the research story. Findings were presented in a relatively straightforward literal telling and through a more fictional/metaphorical account, though she asserts that neither is more truthful or authentic. The latter though was used to represent the findings in a more accessible, engaging and enabling way. It also enabled her to be more honest about some of the power struggles with the adults who she had hoped would facilitate in her dialogue with the children.

Sherwood (2011) placed a similar emphasis on dialogue in her research exploring how parents of young disabled children experienced support. For her, the dialogue came through optimizing her abilities to listen to and attune to the parent-participants and through turning their opportunities to comment on transcripts and other data into conversations. She refers to the process as 'reciprocal meaning-making' in the quest to retain the 'integrity and authenticity of their story and mine' (p. 89). Sherwood's work shows how concerns to use ethnographic case study type approaches to represent insiders' views is at the juncture between everyday qualitative research and inclusive research. The latter comes through in her emphasis on participatory dialogue and reciprocity, her desire to subject her own and her participants' perspectives to challenge in a transactional process in which they might change each other, and in the way in which their stories become intertwined.

The Mosaic approach – description of a method for use with young children

In the next example, the idea of dialogue is expanded to include layers of participants. Here the ideas of Holland et al. (2008) about how the participants experience their participation, and the role of dialogue in inclusive research, have resonance in Clark's (2001) description of the Mosaic approach. This is an approach designed to maximize the involvement of very young children in research about the learning environments that are best suited to them. The Mosaic approach, more codified than organic, is led by the adults in the formal research role but carefully designed to avoid tokenism.

Stage one involves gathering data through observation, child conferencing (a form of interview), using cameras and photos as an alternative language, tours and mapping of the environment, guided walks to get 'local knowledge', and seeking parents' and practitioners' comments. Stage two involves 'piecing together the Mosaic for dialogue, reflection and interpretation' (Clark, 2001, p. 338) in a process of meaning making. This process is carried out through discussion among children, practitioners and researchers – in different combinations and forms. It can involve preverbal children in which case there is more emphasis on observation, attuning to body language, and observations by siblings/other children. Clark (2001) is explicit about the outcomes of Stage two. For children the product is a 'tangible portrait of their experiences', such as photographs,

which are a 'source of pride' together with increased skills and confidence plus a 'chance to reflect' and to raise concerns (p. 339). For practitioners and parents, 'using the Mosaic approach makes the children's experiences accessible to parents in a new way' (p. 340). In addition, practitioners and parents can also 'express their perspectives and gain in confidence' (p. 340). At an institutional level the outcome is a change in culture. The whole process cultivates a 'culture of listening', which means children develop understanding, collaboration is supported and mutual respect is established. Clark contrasts this with a 'culture of measurement', in which 'consulting children aims to extract their preformed views, listening is for adults' agendas only, and practitioners' views are absent in the discussions which follow' (p. 340).

The Mosaic approach is regarded as an inclusive approach with some integrity. It differs from child-led research in that adults play a vital role, but it is strongly guided by a concern with children's agendas and perspectives and by a concept of their competence to hold and share vital knowledge. It is very much about knowledge construction rather than extraction. It positions children as experts, skilful communicators, active participants and meaning makers, researchers and explorers (Todd, 2012) alongside the academic researchers.

Steering groups

Another codified approach to dialogue is the use of steering groups and this is often favoured by funding bodies. The commissioners of the research are, after all, a complicated part of the researcher–researched relationship (Sin and Fong, 2010) and have their own ideas and parameters. In dialogue with inclusive researchers working in diverse ways in the field of learning disability research, it became apparent that one of the features distinguishing academic-led research from lay researcher-led research or partnership research was who funded the research (Nind and Vinha, 2012). Two research funders, Joseph Rowntree Foundation and Heritage Lottery Fund, were particularly attuned to the idea of adults with learning disabilities leading research into their own lives or histories and valued the social inclusion benefits as well as the knowledge benefits gained by carrying out research this way.

More commonly, bodies commissioning research have favoured research led by academics. For example, bodies commissioning research about the

experiences of disabled children, such as the Disability Rights Commission, have slightly different agendas from the Joseph Rowntree Foundation and Heritage Lottery Fund about ensuring that children's voices are heard. 'It behoves us to recognize that aspirations and expectations for, and experiences of, "hearing" from disabled children and young people unfold as a delicate balancing act where different agendas are at work, and where different rights and authority levels are negotiated oftentimes implicitly' (Sin and Fong, 2010, pp. 18–19). Hearing disabled children's voices via funded research has tended to be trusted to academics rather than to disabled adults or to children themselves. This does not mean that those academics have not strived to be authentic in their response to the challenge.

One option favoured by some research funders for making academic-led research more inclusive is the use of reference or advisory groups. Lewis et al. (2008) reflected on the use of such groups in relation to three projects. Lewis et al. (2007) were funded by the Disability Rights Commission to research the experiences of disabled pupils and their families with the aim of identifying the pupils' and families' key concerns and priorities related to education. This involved a reference group of two highly involved disabled people and advisory committees of disabled people. These committees were bigger and less involved than the reference group, but they were already established before the research began. Watson et al. (2007) were funded by the Esmée Fairbairn Foundation to explore approaches by which disabled children with little or no verbal communication could be included in educational decision making. They involved an established reference group of young disabled people – the Listening Partnership – as well as a conventional advisory committee of academics, professionals and parents. In the third project, the Foundation for People with Learning Disabilities and researchers from the University of Cambridge (Byers et al., 2008) were funded by the Big Lottery Fund to conduct PAR with young people with learning difficulties. The aim was to improve the young people's experience through better educational inclusion in mainstream schools and colleges. This project involved support from an advisory committee of professionals, policy makers and parents, and from a reference group of young people from Speaking Up, a local advocacy, training and consultancy organization for young people with learning difficulties. Lewis et al. (2008) reflected on this arrangement, and highlighted the need for care planning for the involvement of advisory group members (including matters of payment). Lewis et al. also reflected that creating, extending or

capitalizing on an existing group to advise projects is valuable, especially when there is a good skills match but the group is not overprofessionalized. Nonetheless, they conclude: 'While there is powerful rhetoric surrounding such work [with reference groups], progress will only be made if honest and transparent accounts highlight the possible complexities and tensions alongside the undoubted benefits' (p. 82).

Urbanfields – the use of participatory video within research

My final example is participatory video, a visual and action-oriented approach that offers a different way of incorporating marginalized voices in research increasingly used by NGOs and fostering deeper engagement with communities. Those particularly interested should also explore this under the labels of participatory film making or community or collaborative video. A specific example comes from Haw and Hadfield (2011) who describe altogether different challenges and solutions to those discussed earlier in their research about the risk repertoires of young people living in 'Urbanfields', an area known for gang and drug culture: 'Our research involved working with these young people on quite sensitive subjects, and so video was seen as a means of accessing their views, without "frightening off" participants through intrusive personal questioning' (p. 100). Their video was not in the form of video diaries as Clarke, Boorman and I used, but culminated in 'two trigger films, six films made by the young people themselves and a final DVD created by the research team' (p. 100). The first trigger video made to recruit participants was shown in the local community centre after extensive leafleting. It was designed to provoke interest by showing the different ways that different groups including professional and media perceive the young people and the risks they take. It challenged the local young people to consider how they would want to portray themselves. It captured and juxtaposed different views alongside the very familiar images of the local area that were needed to prompt recognition and engage interest. Crucial to achieving this, and crucial to the overall study, was the involvement of community-based researchers known within the community who were able to provide an 'insider's view' (p. 102).

In this project six different groups (reflecting differences in dominant ethnic group, gender and age) negotiated the focus of a video they would make to represent their lives, to be owned and used by them. The academic researchers facilitated and researched the video making process, filming it to provide another layer of data for analysis. In a subsequent

phase the researchers' footage was edited with the original trigger video to focus on themes important to the young people and shown as a trigger video to new groups of professionals and young people to elicit responses in focus group and individual interviews. Thus the myths around the local cultures were exposed and reflected upon at different stages and multiple interpretations were explored. Haw and Hadfield (2011, pp. 103–4) reflect on the participants' agency throughout:

As the participants made numerous decisions about the content of their videos, their 'internal narratives', spaces for critical subjectivity, were opened up, reflecting their broader agency. Crucially though, as these videos were produced and shown to different audiences, the potential to enhance this reflexivity and criticality was developed. . . . Getting participants to engage with collectively held myths . . . in their own videos involved incorporating elements, within the video process, of what they considered ordinary and everyday within their locality with what was perceived as extraordinary by those outside it, and exploring why this was so. An exploration of these mythologies relied on the collective experience of the participants and professionals. In this way, the internal and external narratives of the different videos revealed through the production and consumption processes also highlighted the connections between the 'felt' worlds of the participants and how they then fed these back into wider social discourses operating around them.

Learning the art of inclusive research

The examples in this chapter illustrate the range of approaches, methods and skills employed by researchers seeking to conduct their research inclusively in some way. Some of the examples show researchers learning in a formal way about the rules of engagement of research. This may be people new to research, such as children, learning traditional research methods, or people familiar to research, such as academics, learning new ways of relating to and including others (and much in between). Some of the examples show researchers learning through doing, usually from and within the dynamic research teams they have formed, in a kind of apprenticeship or knowledge exchange model. Rarely have the research teams been trained to do research inclusively as such.

Learning through doing is not always straightforward, and Smith (2012, p. 11) recounts indigenous researchers learning through doing who 'get hurt and fail in the process'. In a different context, but addressing similar issues, Warren and Boxall (2009) recognized the lack of training for people wanting to do research in partnerships spanning academics and service users in the field of social work. They therefore describe the rationale for, and development of, their *Researching Together* short course. This brought different groups together to learn from and with each other and to 'raise questions about the "us" and "them" of learning, teaching and research as well as about the idea of "expert knowledge"' (p. 287). The course was prompted by government pushes for service user involvement in social work research as well as policy and practice, and by the authors' concerns 'about the exclusion of many service users, particularly those viewed as "less articulate", from these arenas'. The course created opportunities for undergraduates 'to get to know, share space, communicate with, work alongside, and be challenged by service users', not least because it 'was set up in such a way that the knowledges and experiences of service users were prioritised over the research literature and academic theory which underpins most social policy courses'. This was a conscious alternative to 'objectifying' service users (p. 288), which happens when their knowledge is tacked on rather than embedded in research learning. They used Harding's (2004) idea that dominant groups are 'epistemologically disadvantaged' when trying to research non-dominant groups and their experiences (p. 289).

The *Researching Together* training is unusual in the way that it positions and handles expertise. Warren and Boxall are not alone, however, in recognizing that training is needed. Courses (particularly postgraduate) are emerging in which there is a focus on inclusive, participatory and emancipatory approaches to working and researching. Some of these (e.g. the Norah Fry Research Centre, University of Bristol and Critical Learning Disability Studies, University of Manchester) feature involvement in lecturing by 'experts by experience', thus further blurring the boundaries between academic and lay researchers and teachers. Similarly materials are being developed to support researchers wanting to do research inclusively (see Further reading and resources).

There is much to be learned by inclusive researchers reflecting on their practices and disseminating information about their processes as well as findings. However, this is dependent on the quality of engagement in critical reflection. Sin and Fong (2010, p. 21) argue that: 'Meaningful and successful

involvement will always be a journey of learning, to be approached with humility and conviction.’ Walmsley and Johnson (2003, p. 2) make a strong case that, in the field of learning disability, researchers have stood back from this challenge of critical reflection somewhat, owing to the sensitivity of issues, leading to a ‘certain stifling of debate about the real difficulties of including people with learning disabilities in research’. They have called for ‘certain orthodoxies and assumptions’ to be challenged ‘in order to clarify what inclusive research is and how and where it can be applied’. Grant and Ramcharan (2007, p. 12) have similarly called for those involved in inclusive research to reflect on their experience and on ‘what forms of partnership make inclusive research effective, and whether good science and good inclusive research practice can be brought together’.

Doing Research Inclusively, Doing Research Well? (Nind and Vinha, 2012) was in part a response to the call for collective reflection and to what Walmsley and Johnson (2003, p. 16) identified as a ‘failure to grapple honestly’ with the most sensitive questions. In this study, more than 60 researchers entered into dialogue in focus groups. Recurrent narratives emerged about working in partnership, listening to and learning from each other. Participant-researchers particularly stressed the importance of enabling new researchers by making things accessible, checking things out with them and being honest. From analysis of the transcripts we were able to generate a model (see Figure 3.1) that represents the options for co-researching.

Figure 3.1 Model of working together practices in inclusive research.

Formalized approaches include working with preplanned rules or formal reference groups while improvised (or responsive) approaches are worked out in the doing – responding to challenges as they emerge. Some research teams did both within the same project. Ways of working that emphasized support reflected an inherent assumption that there were experts and non-experts – leaders and supporters – although the basis for the expertise could vary. Supporters would subdue their urges to speak or make decisions, not seeing this as their role. As one supporter (Karen) explained, ‘It’s not always easy, because I may have an opinion . . . but I think that ultimately we make sure the co-researchers make the decisions’ (Nind and Vinha, 2013, p. 5). Ways of working that emphasized negotiation involved considerable time and energy spent negotiating practices and principles for practice before any research could happen. This was sometimes as important to the people involved as the research itself, reflecting their desire to distance themselves from past wrongs or traditional research processes. Ways of working that emphasized interdependency still valued support and negotiation, but these were secondary to co-operation in teamwork involving high levels of trust and communication. Research challenges could be tackled collectively or by allocating roles and tasks according to people’s different strengths. Interdependence came from no-one being regarded as more expert than any other, such that they did not need the other. While the model may be helpful it simplifies diverse practices. These were not fixed according to any one dimension of the model and evolved with greater involvement, critical turning points, exposure to new ideas, or learning from mistakes.

Doing Research Inclusively, Doing Research Well? (Nind and Vinha, 2012) generated various materials intended to support researchers wanting to work in inclusive ways including a prompt sheet of questions designed to provoke reflection and discussion rather than suggest that there is one right way. The questions are listed in Table 3.1.

The research demonstrated the ways in which inclusive researchers are still learning their craft, using the limited possibilities for funded research to enact principled positions as far as practicable. We concluded therefore that ‘it must surely be too early to fix and pin down too tightly the research approach that we call inclusive research’ (Nind and Vinha, 2013, p. 7). Rather than inclusive research ‘becoming the new “normality”’, we argued that ‘an expansive vision of inclusive research is necessary for its sustainability’ (p. 7). In the next chapter I discuss some of the threats to inclusive research and some of the criticisms made of the concepts and practices.

Table 3.1 Questions to ask yourself when working out how to work together in inclusive research

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- 1 Why are you working together on the research? Do you have a shared purpose, or do you want different things from it?
 - 2 What do you each understand inclusive research to be?
 - 3 What values guide the way you want to work together? How will you put those values into action?
 - 4 What terms will you use to describe yourselves (co-researchers, partners, team members, etc.)? What does your choice of the terms say about you?
 - 5 How will you talk about the research? (How often, where, etc.)
 - 6 Who is setting the agenda?
 - 7 Does everyone have equal right to speak? How will you make sure everyone is heard?
 - 8 What skills, knowledge and qualities do each of you offer?
 - 9 What will you do together and what tasks will you need to divide out?
 - 10 What can you plan in advance and where might you need to adapt as you go along?
 - 11 What kinds of support are needed?
 - 12 How will you work through differences of opinion and challenges?
 - 13 How will you learn from each other?
 - 14 Are you placing most importance on support, on negotiation or on interdependence?
 - 15 What will work best for this particular project at this time?
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