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IPAR, an inclusive disability research methodology with accessible analytical tools

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Abstract

Background: Advocates of participatory research for personal liberation and social change emphasise the right of all people to be actively involved as researchers in matters relevant to their own lives. The United Nations' Convention on the Rights of Persons with Disabilities supports this principle, articulating the right of people with disabilities to participate in all levels of society, which clearly includes disability research. Such research may require inclusive research strategies, implemented and analysed by accessible tools, in order to facilitate high-level participation by people *labelled* with learning difficulties. Involvement at this level also challenges commonly held assumptions of incompetence and contests the very construct of *learning difficulties*. Inclusive Participatory Action Research (IPAR), a melding of the approaches of Inclusive Research and Participatory Action Research, challenges traditional research relations where research is done *on* rather than *by* or *with* people labelled with learning difficulties. IPAR establishes more equitable power relations by involving those traditionally viewed as research subjects as co-researchers.

Aims and objectives: To encourage researchers and human services practitioners to consider IPAR as a practical alternative methodology with which to inform disability research design, and to illustrate some accessible analytical tools.

Methods: Theoretical underpinnings of IPAR are discussed and some creative and accessible tools for analysis are presented using a case study of disability research conducted alongside people labelled with learning difficulties.

Implications for practice: The voice of people with disabilities must inform disability research design. Disability researchers must consider including their research participants as co-researchers. The utility and accessibility of creative research methodologies and tools enhance contribution opportunities for these co-researchers. This article provides new ideas that may inform practice in the disability services industry, nursing, healthcare and academia.

- People labelled with learning difficulties have the right to be included in research concerning themselves
- Inclusive methodologies and accessible research tools that facilitate participation of people labelled with learning difficulties as co-researchers in social research are available
- Inclusive methodologies and accessible research tools enable people to demonstrate their abilities and to challenge assumptions regarding who can and cannot conduct disability research, illuminating inaccurate stereotypes that impede best practice

- Inclusive methodologies and accessible research tools can provide access to new forms of knowing

Keywords: Inclusive Participatory Action Research, learning difficulties, social constructionism, photo-voice

Introduction

'Research is a powerful tool...Those who are to benefit (or suffer) from the decisions made by researchers, policy makers and health care administrators should be an integral part of the decision-making process.' (National Health and Medical Research Council and The Consumers' Health Forum of Australia, 2002, p1).

In recent years there has been a growing awareness that the perspectives of healthcare and disability service consumers cannot be ignored by health and human service providers or researchers. Echoing the motto of the Disability Rights movement 'Nothing about us without us' (UN Chronicle, 2004), the right of people with disabilities to opportunities of active involvement in decision-making about policies and programmes, especially those directly concerning them, is now enshrined in international law through the United Nations' Convention on The Rights of Persons with Disabilities (CRPWD) (United Nations, 2006). The purpose of this paper is to encourage practitioners and cross-disciplinary academics to consider Inclusive Participatory Action Research (IPAR) as a viable and rigorous methodology responding to the call for 'nothing about us without us', through which they can explore disability in collaboration with people labelled with learning difficulties. IPAR is a deliberate melding of two participatory approaches, Inclusive Research and Participatory Action Research, into a methodology specifically for researching in collaboration with co-researchers labelled with learning difficulties. The social constructionist theoretical underpinnings of IPAR, including an explanation of the disability theory informing this paper and a clarification of terms such as *labelled with learning difficulties* is provided below along with details of how IPAR was developed.

IPAR necessarily requires inclusive research tools to provide access to research processes and to facilitate meaningful participation of co-researchers. Creative and visual research tools can meet this requirement. The paper presents an IPAR case study with examples of creative research methods, such as photo-voice for data collection and analysis and colour-coding, implemented through patchwork as a means of collaboratively evaluating the inclusivity of IPAR.

As a seasoned practitioner within the disability services sector since 1981, I have worked closely with people with disabilities from the position of *providing a service* rather than from a position of *being of service* (Ferguson and O'Brien, 2005). Undertaking IPAR has taught me the value of altering social relations and of working *with* rather than *on* people, of supporting rather than directing them through the research process. It also taught me the merit of reciprocity and of allowing myself to be guided by my co-researchers. The reflexivity of IPAR helps researchers understand themselves and the social world in new ways, assisting them to develop into critically reflective practitioners (Brookfield, 1995). My reflections on the IPAR process and implications for practice are also provided.

Theoretical paradigm

Before introducing inclusive methodologies it is necessary to establish the theoretical context within which this paper and the research it discusses sit. This is important for understanding not only why inclusive research methodologies were adopted but also for understanding how meaning was made. This paper is theoretically positioned within the social constructionist paradigm. Within the social sciences *disability* is recognised as a socially constructed identity category, similar to *race* and *gender* (Garland-Thomson, 2008). For the social constructionist there is no fixed reality. We understand the

world is socially constructed in an ongoing process as people act upon and interact with their and others' interpretations of the world (Garner, 2007; Gergen and Gergen, 2004). Human differences are instilled with social meanings. Many of those meanings are founded on assumptions that presume 'ablebodiedness' (Chouinard, 1997). In disability theory this assumption is called ableism. Ableism is a set of 'deeply rooted beliefs about health, productivity, beauty, and the value of human life' (Rauscher and McClintock, 1996). These beliefs work to create an environment that is often unwelcoming to people whose ability levels and appearance are socially deemed unacceptably different. In constructing what is and is not acceptable, such ableist attitudes consequently construct people with disabilities as 'other', marginalised, invisible and silenced (Chouinard, 1997). IPAR explicitly challenges ableism by incorporating those historically excluded into research production.

Social constructionism is the antithesis of essentialism (the belief things have an essence which can be defined and understood in the same way by all rational people). Traditionally, disability research has taken an essentialist stance with the assumption that disability was an internal pathology located within the person. This generally unquestioned way of understanding disability is commonly called *the medical model of disability* (Albrecht, Seelman and Bury, 2001). The medical model entrenches inherently unequal power relations. Health and human services are generally founded on the medical model, which places the service provider in a position of power over the service user who is positioned as someone in need.

Over the past few decades the concept of disability has been explored and different ways of understanding disability have emerged (see, for example, Albrecht et al., 2001; Oliver, 1990, 1996; World Health Organization, 2012). Among a number of alternatives to the medical model proposed, is the *social model of disability*. This model asserts that people are disabled by society and its imposition of physical, social and attitudinal barriers (French, 1994). The social model makes a clear distinction between disability and impairment, as articulated below:

> *'Disability is not something individuals have. What individuals have are impairments... Disability is the process which happens when one group of people create barriers by designing a world only for their way of living, taking no account of the impairments other people have.'* (New Zealand Ministry of Social Development. Office for Disability Issues, 2001, p3).

Although still not receiving much recognition within human services in Australia, the social model of disability has gained significant global currency in recent years and underpins the United Nation's Convention on the Rights of Persons with Disabilities (the Convention), which recognises:

> *'...that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.'* (United Nations, 2006. Preamble, point e).

So, from a social constructionist position utilising a social model of disability, what are the implications for research? First, ableist language must be identified. Taking a social model position in this paper, I am using the term *learning difficulty* rather than *intellectual disability* (which is generally used by Australian disability service providers and their funding bodies (New South Wales Department of Community Services, 2007). This removes the notion of disability with my co-researchers. *Learning difficulties* is also preferred by many people within the People First movement (People First, 2008). It acknowledges that people can learn but that for some, learning can be difficult. People labelled with learning difficulties have complained that

'In the past we used to be called labels like mentally handicapped, mentally retarded, intellectually handicapped, or mentally subnormal. We didn't like these labels as they kept us down. We choose to use 'learning difficulties' ourselves. It is a label which doesn't hurt us as much as those above. Jars should be labelled not people.' (Central England People First, 2000).

Therefore, using *learning difficulties* conforms to the vernacular of many people thus labelled and is in keeping with the emancipatory research intent by respecting the right of people to choose how they wish to name themselves. As far as my co-researchers were concerned, they did not see themselves as people with disabilities because disability was understood to be related to physical limitations. As one of my colleagues observed, 'we're not in wheelchairs or nothing'.

Following the example of Riddell, Wilson and Barton (2001) of avoiding a clinical definition of learning difficulties, I instead adopted an 'operational definition' when designing the IPAR discussed in this paper. The eligibility criteria chosen for the IPAR co-researchers were that they were eligible and receiving assistance from services for people labelled with learning difficulties.

This paper is based on the understanding that learning difficulties is a social construct imposed on one group of people by others and is not an essential characteristic of a person or an internal, diagnosable affliction such as measles (Ferguson, Ferguson and Taylor, 1992; Rapley, 2004; Rioux, Bach and Allan Roeher Institute, 1994). *Learning difficulties* is just a label.

The second implication of such an epistemological position is that the co-researchers should not be *disabled* by exclusive, ableist research strategies. To explain how I responded to this implication, I present IPAR. Beginning with an overview of the two primary research approaches underpinning IPAR, I note commonalities and differences before explaining why IPAR best suited my research purposes.

IPAR, an inclusive disability research methodology

Collaborative research covers a number of research paradigms that assist the active participation of people in research concerning themselves (Ollerton, 2011). The methodology adopted in the research discussed here comprised a deliberate melding of Inclusive Research (Walmsley and Johnson, 2003) and Participatory Action Research (McTaggart, 1994) into an approach I called Inclusive Participatory Action Research (IPAR) (Ollerton, 2011).

As an emerging paradigm in the field of disability studies, Inclusive Research responds to the disability rights movement's catch cry 'nothing about us without us'. Inclusive Research incorporates as co-researchers people labelled with learning difficulties. Such people have historically been viewed as objects of research. The paradigmatic shift of Inclusive Research is away from ableist processes that privilege the voice of the medical professional and towards those with learning difficulties, acknowledging them as experts on what it is to live with such difficulties (Walmsley, 2001; Walmsley and Johnson, 2003). They are recognised as co-researchers contributing in whatever capacity they have (see for example, Atkinson and Williams, 1990; Johnson, 2009; Roets and Goedgeluck, 2007; P. Smith, 1999; Williams and Heslop, 2005; Williams, Ponting, Ford, and Rudge, 2009). Inclusive Research recognises 'that intellectual impairment does limit the degree to which people can be involved in certain activities which require a high degree of abstract reasoning' (Walmsley, 2004a. p54). Inclusive Researchers do not claim a neutrality of power relations as they work alongside their co-researchers (Brooks and Davies, 2008), but do work to minimise an unequal power structure (Walmsley, 2004b). One way of doing this is by actively finding 'ways for researchers with learning difficulties to do things for themselves' (Williams, Simons, and Swindon, People First Research, 2005).

Inclusive Research has no fixed formula. Importantly, Inclusive Research permits non-disabled researchers to identify a research problem and bring it to the community of people labelled with learning difficulties to see if they consider it worthy of investigation (Chappell, 1998). The research topic is owned, though not necessarily initiated, by the Inclusive Research team (Walmsley and Johnson, 2003).

Participatory Action Research, on the other hand, is generally something that originates within the research team, be it in a classroom, an organisation or community setting. It is not necessarily disability-related research. Participatory Action Research is practice-based and aims to transform both theory and practice, developing each in relation to the other, critically exploring theory and practice and their consequences (Kemmis and McTaggart, 2003). Participatory Action Research is similar to Inclusive Research in recognising the expertise of the participants and strives to break down the distinction between the researchers and the researched. However, it differs markedly from Inclusive Research in that it always involves iterative cycles where research, action and reflection are interlinked. It is not only about knowledge creation but also education, consciousness development and action for positive social change (Gaventa, 1988; L. Smith, Rosenzweig and Schmidt, 2010; Wadsworth, 1998). Although the iterative cycles are a key feature, the criterion for success of Participatory Action Research is not found so much in following the cyclic processes but in achieving an authentic sense of practice development, along with a deeper understanding of practice and the settings in which they occur (Kemmis and McTaggart, 2003).

Participatory Action Research has a rich history of being actively involved in the journey for personal liberation and social change along with human rights activism (Kemmis and McTaggart, 2005). Participatory Action Research adopted by Latin American adult educators and social scientists, such as Freire (1996) and Fals Borda (1988) engaged in collaborative processes of investigation, education and action with poor and oppressed groups. Their goal was to transform community and societal structures to improve the lives of the oppressed (Gaventa and Cornwall, 2001). Freire's (1996) approach to Participatory Action Research, which is grounded in liberatory pedagogy, was incorporated into my approach to the research so that an awakening of critical consciousness might be the educational outcome for the research team.

Commonalities
Both Participatory Action Research and Inclusive Research fundamentally challenge presuppositions about the nature of research and conventional research practices, including who can undertake research. Both methodologies alter traditional research relations by allowing people agential roles in constructing and reconstructing of their own social reality with 'their own hands' (Kemmis and McTaggart, 2003). As participatory methodologies, they each draw on adult educational principles of learning by doing.

Differences
The following table highlights significant differences in the methodologies.

Table 1: Differences between Inclusive and Participatory Action Research

INCLUSIVE RESEARCH	PARTICIPATORY ACTION RESEARCH
Undertaken in collaboration with people labelled with learning difficulties	Not specifically in collaboration with people labelled with learning difficulties
Inclusive Research has no fixed formula	Characterised by iterative 'plan, do, review, revise' critically reflective cycles
Inclusive Research is not necessarily practice based	Research is practice based and aims to transform both theory and practice
Co-researchers do not have to initiate the research problem	Research problem generally identified by the participant group
Social change is not always the goal	Positive social change is always the goal

Since I was specifically developing a methodology for co-researchers labelled with learning difficulties, Inclusive Research suited. However, incorporating the iterative cycles of planning, action and reflection added a critically reflexive edge to the methodology that increased the likelihood of the raising of co-researchers' critical consciousness for personal liberation. Thus, the research could be described as: Inclusive + Participatory Action Research = IPAR.

My intention of an IPAR approach was also to be a means by which the right to self-determination could be expressed, explored, claimed and gained by the research team. By using an IPAR methodology I recognised that people labelled with learning difficulties had the right to name the world as they saw it and the right to the support required to do this (Freire and Macedo, 1987; Ollerton and Horsfall, 2012). It recognised the right to accessible research methods which were both rigorous and facilitated means by which the research team could collect and analyse data and communicate the findings. The following case study explains how IPAR was implemented.

Case study
Background/rationale
The research methodology and research tools discussed in this paper were part of a doctoral project, which received human research ethics approval from the University of Western Sydney, Australia. Although a doctoral student, I was also a vocational trainer for people labelled with learning difficulties within the disability employment assistance sector. I had observed that social systems and government regulations, such as the job-searching obligations linked to welfare benefits (Department of Families Housing Community Services and Indigenous Affairs, 2010), frequently limited opportunities for self-determination, perpetuating dependence and compliance. Aligned with Wehmeyer's definition, I understood self-determination as 'acting as the primary causal agent in one's life and making choices and decisions regarding one's quality of life, free from undue influence or interference' (Wehmeyer, 1999, p57).

A person's level of self-determination is affected by the degree to which their environment provides opportunities for them to practice self-determination and exercise skills of self regulation, self-realisation, autonomy and psychological empowerment (Wehmeyer and Bolding, 2001; Wehmeyer and Schwartz, 1998). People with learning difficulties tend to have poorly developed self-determination skills and their lives are often largely controlled by others (Wehmeyer and Garner, 2003). I recognised environmental barriers within the context of my own workplace that hindered service users' decision-making and choice, and reduced their control over their lives. In designing my doctoral research project I wanted to provide an opportunity for people labelled with learning difficulties and who possibly lacked self-determination skills, to explore from their own perspective the things that hampered their self-determination (Ollerton, 2011). There was a deliberate

emancipatory intention to provide opportunity for people to name their world in order to change it (Freire, 1989). I also hoped that researching would present people with occasions for exercising and thereby developing self-determination.

The research was necessarily collaborative and I planned to take the position of research facilitator rather than chief investigator. Instead of leading, I hoped to encourage leadership from within the research team. In this doctoral project my personal aim was to facilitate an inclusive research project, exploring barriers to self-determination. What those barriers were and how they would be explored would be decided by the research team. This created a paradox. As a doctoral student, inclusively researching was part of a larger research undertaking, the doctoral programme. I was part of a team and yet also had to stand back independently and assess the inclusive research project. I anticipated that my aim to explore social barriers to self-determination would become shared as the research team members began to explore their own barriers. Thus, together we would share a common aim. Working alongside people as co-researchers rather than research subjects was intended to provide opportunity for shared decision-making and planning, and for the establishment of more equitable and democratic research relations than is usual in social research based on a medical model of disability.

The IPAR project

Thirty months of research began in April 2007 after five people aged 18-23, all of whom had all been previously identified as having mild-moderate intellectual disabilities by Australian disability service providers, self-referred to an information session on the proposed research. This had been advertised through disability service providers, community centres and local library notice boards. The objective was that people could self-determine to attend. Following the information session, attendees were invited to register their interest in the project and voluntarily join the research team. Since joining the project was voluntary, opting out of the research at any time was also possible and clearly stipulated on the consent forms and reiterated throughout the project.

Co-researchers were supported to investigate aspects of their environment which they believed stopped them from having control of their own lives. This aim sat well with point (n) of the Convention on the Rights of Persons with Disabilities' Preamble, which confirms 'the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices' (United Nations, 2006. Preamble, point n).

Using accessible analytical tools

In order to render the research process accessible to the co-researchers and forge pathways of knowing, a range of creative, inclusive, and analytical methods were used. Much research relies on text-based data and abstract concepts. These can be exclusive to people labelled with learning difficulties. I needed inclusive tools that did not rely on reading skills and which made concepts concrete. I also needed tools that encouraged sharing of power and responsibility. The creative methods used included: role-play to teach research ethics; photography to develop pictorial texts for institutional ethnographic examination; metaphor to assist people in articulating meaning within their photographs; poetry to analyse and make meaning from data; photo-voice as a data collection, analysis and dissemination tool; and colour-coding using patchwork as a means of evaluating the inclusivity of the IPAR process. For the purposes of this paper I will not discuss how each of these methods was used. This paper concerns IPAR and its creatively visual evaluation process. However, as photo-voice was a primary method, a brief overview is provided. For a comprehensive review of the photo-voice aspect of this research see Ollerton (2011), and Ollerton and Horsfall (2012).

Photo-voice

Photo-voice is a photography-based research technique developed by Caroline Wang during the 1990s (Wang, 1999; Wang and Burris, 1997). Its benefit as an Inclusive Research tool that emphasises action over cognition has been recognised (Booth and Booth, 2003). Although not widely used, photo-voice has been used by others undertaking research with people labelled with learning difficulties (Booth and Booth, 2003; Jurkowski, 2008; Jurkowski and Paul-Ward, 2007; Woolrych, 2004). Photo-voice was the primary data collection method used in the IPAR and was also valuable as a means of critically analysing data through discussion of the photos. It is an excellent means of encouraging self-determination, as the photographer is responsible for choosing what, when and why they take a particular photograph. Photo-voice facilitates autonomy (people decide what to photograph), self-regulation (organising themselves actually to take the photograph), self-realisation (people have a story to tell and the skills and tools to do it), and psychological empowerment (they can tell their story and someone will listen).

In practical terms photo-voice involves 'giving people cameras and using the pictures they take to amplify their place in and experience of the world' (Booth and Booth, 2003). This elevates the participant to the status of expert in the analysis of their own lives, instead of merely making their lives available for analysis by others (Wang and Burris, 1997). It prioritises the voice of people from marginalised communities to understand better individual and community concerns (Poudrier and Mac-Lean, 2009).

Photo-voice proved to be a springboard for action once the research problem, a specific social barrier to self-determination identified by and agreed on by the research team, was articulated. The weekly IPAR meetings were times in which we asked why the barrier was there, who benefitted from it, what had already been done to remove it and what we might do as a group to have its limiting influence reduced. They were times of collaborative brainstorming, planning, implementing actions, analysing our results and reviewing our progress. I found that my co-researchers had a lot to say about their social barriers and were keen to discuss, initiate ideas and take up research responsibilities. Sharing power in this way reduced some of the burden of facilitating the research project. It provided me with access to the insights of these experts on what the issues were, and with the opportunity to be taught by them and to plan collaboratively how we would explore the social barriers. These research actions included: designing and implementing surveys; interviewing disability service staff; exploring information about disability rights through advocacy and self-advocacy services and police stations; lobbying local politicians about services needed; writing letters of concern to state and federal ministers and the Disability Discrimination Commissioner; plus numerous letters of complaint to a disability service provider and frequent liaison (by me) with a disability rights legal advisor. All these actions involved active citizenship and they contributed to a growing awareness within our whole team of disability rights and unchallenged areas of injustice. As I shared my research skills with the team, they shared their lives and experiential knowledge with me. It was this reciprocity that drove the research forward.

Our research findings were disseminated to the co-researchers' audiences of choice. These included the development of a research project website and presentations to disability service providers, New South Wales' Department of Education representatives and special school classes in Western Sydney, using a PowerPoint presentation collaboratively developed by the whole team. The research team also co-presented its findings at a number of conferences across Australia, including the 2009 'Having a Say Conference' (the largest disability services consumer conference in the southern hemisphere, with more than 1000 delegates), and three academic conferences. Travelling to interstate conferences took money and considerable planning. However, the IPAR structure was empowering for my co-researchers and they were all highly motivated, actively planning and undertaking fundraising activities, often without my assistance, producing and managing their own

research resources. This is quite extraordinary and meant that ours had developed into a self-determining IPAR team.

As the research project unfolded amid what seemed like perpetual activity, I stood back, as an independent researcher, to analyse the doctoral IPAR project, and reflexively assess its inclusivity. Colour-coding proved a useful means for visually evaluating just how collaborative the IPAR was.

Accessibly analysing IPAR

IPAR is founded on an inclusive ideal. It requires research tools that are accessible to people with differing skill sets and which are capable of including co-researchers in the whole research process, including its evaluation. This section considers a creative, visual means of interrogating the inclusivity of IPAR. Although primarily designed for my own reflection, in an attempt to discern whether or not our research had been as collaborative as I had intended it to be, colour-coding implemented through patchwork emerged as an effective means of making the abstract tangible and the theoretical visual, and as method that could be easily used by co-researchers.

Although the IPAR facilitator endeavours to share the role of undertaking or authorising actions with co-researchers, in practice many of the responsibilities fall to the facilitator. In our case this was because I had the literacy skills required to write letters and the internet access to send emails or to set up meetings with others. I was also the student with a vested interest in ensuring the project was completed on time. A criticism of research actively involving people with learning difficulties has been that it is not sufficiently inclusive (Rodgers, 1999), can be tokenistic (Radermacher, 2006) or even stage-managed (Riddell, Wilkinson and Baron, 1998). As the research facilitator I was mindful of these criticisms and also of the fact that my co-researchers felt that my voice had authority and that my suggestions carried weight. Therefore, in my capacity as a doctoral student rather than as the IPAR facilitator, I attempted to assess whether or not my voice had carried too much weight and if I had led rather than facilitated the research.

I employed a colour-coding strategy using the art of patchwork as a hermeneutic analytical tool with which to communicate with the collaborative spirit of the research and to analyse visually the extent of the IPAR collaboration. The patchwork-article created represented a research report. Actions and events were symbolically represented in colour-coded squares.

I began by chronologically charting research data from meeting minutes, emails, personal journal notes and field notes. Such data included who made suggestions to issues arising, and which actions were being undertaken by me independently, the group as a whole or by me under the directions of the group. Issues and actions were colour-coded. Five colours were allocated to symbolise each of the actors involved in the research, with my co-researchers represented by a single coloured patch. By identifying and scrutinising my independent actions alongside those carried out by me in collaboration with co-researchers, and actions completed by individual co-researchers, I hoped to expose any imbalance in the collaboration process. Colour-coding data also highlighted the various actors with whom we had interacted. My aim was to distinguish one action from another at a glance by removing the detail in order to gain an overall impression of the research process.

Starting at the bottom of a large sheet and working from left to right, coloured sticky notes (7.5cm square reusable labels) were placed chronologically in rows of ten. By the end of 14 rows (140 sticky notes) I had a good impression of the dominant colour. The analysis sheet was displayed for several days in my study enabling me to reflect on it while also allowing the colour-coded analysis to speak to me. I wanted to see it (up close and from a distance), to think on it (both deliberately and subconsciously) and allow the colours to communicate to me in some way. On reflection I became uneasy that my initial approach had been too simplistic and required refining. Further colours were

introduced to represent stakeholders and influences on the research previously omitted, and a new colour-coded analysis was conducted.

I might have left the analysis there, counting the colours and tallying the results – content with the fact that the co-researchers' patches had prevailed, the project had been collaborative and I had achieved my aim. But I was not content. The result did not articulate clearly enough the social action journey and I felt that there was more to be said. The sticky note colour-coded analysis had proved useful but the resources I had employed did not adequately convey the whole story or effectively demonstrate the power of this visual analysis tool. I wanted to reconstruct the analysis with more carefully chosen colours in the hope that this would give me a more accurate visual summary of the research process. I decided to move from sticky notes to fabric. Another reason for moving from paper to fabric was that even if my first attempt at a colour-coding analysis had been completely satisfactory I was not convinced that coloured sticky notes stuck onto large sheets of paper would inspire anyone. I decided to turn the sticky note analysis into a practical keepsake, a patchwork throw that could be re-used as a teaching tool and shown to others as an analysis strategy to be shared.

I spent time deliberately choosing fabric that captured the essence of the actor it symbolised. For example, although initially intending to produce a patchwork analysis in shades of purple, I was intuitively drawn to a roll of autumn-coloured fabric. The multi-coloured fabric metaphorically signified a diverse group of people. With many different colours working so beautifully together, it also represented the collaborative and cooperative nature of our research team. The research had been a season in our lives, which was also captured by the autumnal colours. Since the pattern on the fabric depicted a garden I felt the personal growth experienced by each of us was symbolised in the fabric. The patchwork throw was assembled according to the sticky note template.

Figure 1: Patchwork analysis

On 30th January 2008, a roughly constructed throw (see Figure 1, above) was presented to the research team. I described to the co-researchers the various meanings of the coloured patches and why I had undertaken the analysis. I was unsure whether the concept behind this analytical tool would be too complex for the research team to grasp, but hoped it was accessible. The group unsettled my assumptions by demonstrating great interested in the throw and asking many questions about each of the squares.

One co-researcher laughed as he identified a particularly difficult barrier we had repeatedly encountered 'Oooh. Look at all the [specific barrier]s! What were these ones? [pointing to two green squares side by side]'. Another asked 'who are all these orange ones?' The co-researchers even critiqued the throw with another co-researcher complaining 'What about [another barrier]? That was my main issue. I think I should have had a patch as well'. This just criticism revealed that the evaluation process could have been done collaboratively and that co-researcher input would have given it greater depth and accuracy.

Following our discussion of the throw it was evident that the co-researchers recognised that the patches represented different people. They counted each of the patches and recorded how many of each colour was found in the throw. By visually representing the co-researchers' actions and then comparing these with other actions and incidents depicted in the throw, the team was able to see, quantify and understand the extent of collaboration in the research. The group members were able to determine visually and quantitatively for themselves that their patches dominated the research process. One co-researcher commented, 'Janice has 19 green ones and 24 half-half ones'. His colleague added, 'but we've got more. We've got 37'.

Another interesting outcome of the patchwork throw analysis was the way in which it visually demonstrated increasing group activity. As the research progressed (and the throw grew), the number of co-researcher/autumn patches increased. The patchwork analysis demonstrated that as the co-researchers gained skills and confidence they initiated more co-researcher actions.

The research continued for another 18 months after the introduction of the patchwork throw and there was a sustained interest in and identification with the patchwork process, and a clear understanding that the group's actions were abstractedly reflected in the throw. Over the following months co-researchers enquired how the throw was developing. On one occasion, commenting on a particularly busy period of research one of my colleagues said 'that throw must be a bedspread by now'. This remark demonstrated not only an understanding of the link between the patches and the co-researchers' actions, but also a recognition of the growing size of our project.

Collaboratively colour-coding

The use of colour-coded or patchwork analysis lends itself easily to a collaborative endeavour where the whole process is shared, rather than undertaken individually, as I had done. Co-researchers could be incorporated in the charting and colour-coding of data. This could be undertaken in conjunction with IPAR meeting minute-taking. Actively involving people to identify the colour with which to code specific actions not only highlights the colour-coded person's role in the research (pointing to valued status), it gives non-readers access to the minutes and a means by which they can keep one another accountable and on task. Furthermore, co-researchers can take responsibility for evaluating the inclusivity of the project later on. If developing the evaluation into a patchwork item co-researchers could be involved in choosing the fabrics and, where there is interest, assembling the throw. However, for the practitioner not drawn to sticky notes or sewing, the colour-coded analysis concept can be readily replicated on a computer-based document within a colour-coded table. Colour-coding, implemented through patchwork, was a creative and accessible way of analysing the collaborative nature of the project with people labelled with learning difficulties. The

colour-coded product embodies a research report that can be symbolically read to others by co-researchers because it does not rely on literacy skills and can utilise symbols of their own choosing. It is a report that could be mounted as a wall hanging celebrating IPAR. Using colour-coded analysis in our research not only indicated that, overall, the research had been genuinely and successfully collaborative, its acceptance by the research team dismantled yet more of my unchallenged assumptions about my co-researchers. Their ability to understand the patchwork evaluation flies in the face of stereotypes of people as lacking perception (Weinberg, 2007), as inarticulate (Finlay and Lyons, 2001) and as incompetent. This confirms the findings of Welsby and Horsfall (2006) that people labelled with learning difficulties have valuable contributions to make and with support are able to undertake social research.

Implications for practice

All people, including those labelled with learning difficulties, have a right to be included in all levels of society, including research. This case study has shown that inclusive methodologies, such as IPAR, using accessible analytical tools, allows people labelled with learning difficulties to participate as co-researchers. Making use of IPAR and accessible research tools can demystify research and open the way for more people to participate in it. This in turn, will enable people to demonstrate their abilities and to challenge assumptions regarding who can and cannot do disability research. It will illuminate inaccurate stereotypes that are currently impeding best practice.

Photo-voice is a versatile tool that encourages the exercising of self-determination skills and promotes autonomy. I commend it as useful for other practitioners and researchers as it provides a window into the lives of people while ensuring that they maintain control of the vista. Colour-coding is a visually creative means of quantifying and analysing data that does not exclude non-readers. It was successfully used to collaboratively evaluate IPAR and is a tool that can be used in other ways, such as in recording meeting minutes.

Within the context of IPAR such creative methods are important as they can provide access to new forms of knowing. They facilitate the co-researchers' contributions and are a means by which people can dispel the myths of incompetence, reconstructing the construct of learning difficulties. However, the contribution of IPAR and creative methods are not confined to disability research. Using IPAR as a model and accessible tools as a means, people labelled with learning difficulties can also make valuable contributions to programme, practice and policy production.

Conclusion

People labelled with learning difficulties have the right to be included in research concerning them. Indeed, documents such as Australia's *Statement on Consumer and Community Participation in Health and Medical Research* and the Convention on the Rights of Persons with Disabilities call for their inclusion (National Health and Medical Research Council and The Consumers' Health Forum of Australia, 2002; United Nations, 2006). It behoves us then, as researchers and practitioners, to find ways of facilitating this involvement. Positioned within an emancipatory research paradigm, the case study presented here had an explicit intention of researching in partnership with people labelled with learning difficulties. IPAR was presented as a viable, rigorous alternative to a medical model of disability-based research methodology. The IPAR discussed in this paper made use of a variety of creative and inclusive research tools, which made the research process accessible to and inclusive of people labelled with learning difficulties. This opened access to new ways of knowing for everyone involved.

Photo-voice was introduced as a means by which IPAR practitioners can facilitate active participation of co-researchers and enable their voices to be heard. In doing so, the co-researchers play an active

part in the dismantling of, and their own liberation from, inaccurate stereotypes. In this way they actively reconstruct the construct of learning difficulties.

Colour-coding complements IPAR and may prove useful to other reflexive practitioners and researchers aiming to be more inclusive in programme planning or research. Colour-coding was a simple, accessible and an effective means of quantifying actions that enabled the whole research team to evaluate the authenticity of our research collaboration.

I encourage practitioners and cross-disciplinary academics to consider IPAR as an alternative methodology through which the research process can be made accessible to people labelled with learning difficulties. Accessible analytical tools can facilitate their contributions, opening up new ways of knowing and ensuring researchers respect the call for 'nothing about us without us'.

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A commentary by Ruth Northway follows on the next page.

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COMMENTARY

IPAR, an inclusive disability research methodology with accessible analytical tools

Ruth Northway

Approximately eighteen years ago I first became aware of participatory research approaches and started to question why people with learning difficulties had, historically, been assigned a passive role in other people's research. Prior to this point (when I became aware of some of the critiques concerning traditional disability research) I had not questioned why the voices of people with learning difficulties had been marginalised or excluded and why, if we wanted to know about their lives, researchers had tended to ask other people. Research courses I had undertaken had not explored such issues and I was not aware of what I did not know.

Since then I have had the privilege of working with people with learning difficulties and people with mental health problems to plan, undertake, and disseminate research. Over this period I have witnessed a growing interest in such research and an increase in published papers reporting not only the findings of participatory studies, but also sharing experiences of how teams have worked together to undertake research. This latter focus is important since within participatory approaches, new knowledge arises not only from the collection and analysis of empirical data but also from the process of working together to plan and undertake such research. Furthermore, since it is still a relatively 'young' research approach, publication of findings relating to this process is essential for the further development of this approach, hence the importance of the issues discussed in this paper.

The author highlights how, traditionally, people with learning difficulties have been excluded from the research process due to the assumption that they cannot 'do' research. Nonetheless, as noted above, recent years have seen such a perception challenged as people with learning difficulties increasingly take on the researcher role. However, to facilitate this it is important to identify barriers within the research process and to find the means of making adjustments where they are required in order to promote inclusion and participation. In this paper the author has highlighted two potentially useful strategies, namely Photo-voice and the use of patchwork to support analysis. Photo-voice has been used in a number of studies involving people with learning difficulties and offers a strategy by which issues of concern can be captured from the perspective of those involved. Moreover, the physical presence of a photograph can greatly assist analysis as it provides a tangible reminder of the issue, person, event, or object, thus reducing reliance on recall and abstract discussion. The use of a patchwork to support analysis is a highly creative approach and, while visual methods have been used elsewhere, I have not come across this specific strategy. In this study the patchwork was introduced by the author after she had undertaken some initial work on it. It would be interesting to see how it could be used in subsequent studies by involving co-researchers in its creation from the outset.

Over the years I have read widely concerning participatory research, disability research and learning difficulties research. One thing that has regularly struck me is that, while discussions concerning disability research explore participatory and emancipatory research approaches, they rarely make reference to the wider literature concerning participatory research. Moreover, debates concerning learning difficulties research often fail to make reference either to this literature or to the debates concerning disability research. This feels like a missed opportunity since issues of marginalisation and oppression, and the potential of research to challenge and transform power relations, are relevant to, and discussed within, each of these areas – albeit to different extents. This paper addresses this deficit to some extent by noting the origins of participatory research approaches as lying in the work of people such as Freire and Fals Borda. Nonetheless, while there is discussion concerning inclusive and participatory approaches to research involving people with learning difficulties, wider debate concerning disability research is absent.

The author of this paper proposes that she has presented an original research approach, namely Inclusive Participatory Action Research (IPAR), this being a hybrid of Inclusive Research and Participatory Action Research. However, within the wider literature there is already a plethora of terms used to refer to a range of research approaches that share many common features; participatory research, community-based participatory research, Participatory Action Research and emancipatory research. While some would argue that these are distinct approaches, others feel that the differences are in terminology rather than substance. Participatory approaches by definition are inclusive, and while the issues to be researched are usually identified by the community, this is not always the case, and not everyone is required to participate in the same way at all stages of the research process. Furthermore the author suggests that social change is not always the goal of Inclusive Research, yet the very act of seeking to make research more inclusive is achieving social change. Given these issues, I am not entirely convinced of the value added by introducing yet another term for a research approach. However, in stating this, I am conscious that the author is probably only able to present a limited version of her rationale in this paper, and that further discussion may strengthen that rationale. It will be interesting to see the extent to which IPAR is taken up by other researchers as a distinct research approach.

The major implications of this paper would appear to relate to the development of research practice, as it offers guidance regarding participatory approaches to research. The focus here is on working with people with learning difficulties but the approaches discussed could usefully be applied with other groups of people, such as children. However, as the author acknowledges, collaborating with others to undertake research such as this leads practitioners to reflect critically on their wider professional practice, challenging their assumptions and thereby developing and improving their practice. The practice implications of participatory research thus occur at many levels, both within and outside the research process.

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A response to this commentary appears on the following page.

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RESPONSE TO COMMENTARY

IPAR, an inclusive disability research methodology with accessible analytical tools

Janice Ollerton

The commentator's thoughtful review is welcomed. I too will be interested to see patchwork/colour-coding incorporated into research designs to enable researchers visually to assess actions from the outset of a research project. While colour-coding and the charting of actions complements standard research record keeping, for example team meeting minutes, or can be incorporated into Gantt charts, I look forward to seeing others build on these ideas with further applications and innovations to promote a more equal distribution of power between research team members.

The commentator notes that disability literature rarely makes reference to 'wider literature concerning participatory research'. This article links the Participatory Action Research goal of transforming community and the lives of oppressed people (Gaventa and Cornwall, 2001) with research informed by the theory of ableism. Ontologically, approaching the research from a social model of disability position recognises that people labelled with learning difficulties are frequently marginalised and oppressed within and by a society that privileges cognitive skills. Furthermore, this article explicitly introduces learning difficulties into the wider adult education and human rights debates on social oppression by drawing on Freire (1996) and the right to name the world for oneself (Freire and Macedo, 1987). It explicitly challenges ableism and builds consciousness-raising outcomes into Inclusive Participatory Action Research (IPAR).

I agree with the commentator that the act of making research more inclusive achieves social change. In this respect, the difference between Inclusive Research and Participatory Action Research is perhaps more one of emphasis. In the former, such change is usually regarded as a positive outcome whereas social change is an overt research aim of Participatory Action Research.

Unfortunately, journal space restrictions often mean that interesting and relevant issues cannot be fully explored in every publication. For the interested reader, further analysis and comparison of a range of participatory methodologies in the broader context of disability studies is given in Ollerton (2011). I intend to present this discussion in a future publication.

Reflecting on the commentator's observation that there is already a 'plethora of terms used to refer to a range of research approaches that share many common features', I would maintain the importance of IPAR's distinction. IPAR stems from two primary methodologies. 'Capital I' Inclusive Research is distinct from other methodologies that strive to be 'inclusive' as it only collaborates with a specific population – people labelled with 'learning difficulties'. It is exclusively inclusive. Participatory Action Research overlaps but is clearly recognised as a distinct methodology. IPAR

provides the theoretical underpinnings explicitly to incorporate a 'praxis-oriented dimension' (McLaren, 1987, p 136) into an Inclusive Research approach.

Similarly, and even more explicitly, emancipatory research within the context of disability studies is a distinct methodology with defined criteria. It demands that disabled people initiate and control all aspects of the research process, including social and material relations (Barnes and Mercer, 1997; Oliver, 1997). Although our research had emancipatory ambitions, since I initiated and was funded to undertake the research, it did not qualify as emancipatory research.

Finally, I also share the commentator's dislike of unnecessary terms. Nevertheless, accurate and precise language is important, academically and socially. In my own academic journey I found the distinction between Participatory Action Research and Feminist Participatory Action Research particularly helpful as it clearly delineated and focused on the research priority. It is my hope that researchers will also find the distinctive research methodology of Inclusive Participatory Action Research to be a useful refinement.

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