

The practical wisdom of inclusive research

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Abstract

The concept of inclusive research epitomizes the transformation away from research *on* people, to research *with* them. Applied particularly but not exclusively in the field of learning disabilities, the concept encapsulates the drive to involve people in the design and conduct of research about them, reach and represent their lived experience, respect them and value different ways of knowing. This paper discusses some of the challenges that UK inclusive researchers have shared in focus groups aimed at taking stock of this transformative movement and it shares how a local UK research collaboration between academics and people with learning disabilities has addressed some of these challenges. Inclusive research methods of generating and analyzing data are examined within the broader context of how research projects and partnerships are enacted. The paper concludes that doing research inclusively is gradually transforming through collective practical wisdom and praxis.

Keywords: inclusive research; participatory research; learning disabilities; praxis; phronesis

Introduction

I write this paper from my perspective as an academic researcher, methodologist, educationalist and long-term advocate and collaborator working with people with learning disabilities. These multiple roles and identities inform a discussion of the collective practical wisdom developing among researchers, with and without learning disabilities, who are doing research inclusively. I begin by expanding on some of the key terms used in the paper, before describing the research underpinning the argument I develop about where we have got to in inclusive research in the learning disability arena and what this means for inclusive research more widely. The paper shows how and what practical wisdom being generated among inclusive researchers in the learning disability field has been teased out and, equally importantly, places it within this special issue to sit alongside and be read in interaction with discussions of democratising research developments with other groups.

The term inclusive research has a relatively short history in its explicit use pertaining to doing research *with* people with learning disabilities. Jan Walmsley used it in her 2001 paper and it was used more widely following the publication in 2003 of her book with Kelly Johnson, *Inclusive Research with People with Learning Disabilities: Past, Present and Futures*. Thus, a change in the relationship between research and people with learning disabilities was named, reflected upon and even critiqued. Walmsley and Johnson (2003, 10) depict inclusive research as that which 'involves people who may otherwise be seen as subjects for the research as instigators of ideas, research designers, interviewers, data analysts, authors, disseminators and users'. Moreover, they establish some distinguishing features:

- The research problem is owned by disabled people
- It is conducted to further their interests and address issues which matter to them and ultimately lead to improved lives for them
- It is collaborative, involving people with learning disabilities in the process of doing the research and accessing and representing their views and experiences

- People with learning disabilities exert some control over process and outcomes and are treated with respect by the research community
- The research question, process and reports are accessible to people with learning disabilities. (Walmsley and Johnson, 2003, see pages 16 and 64)

I have somewhat amplified the original depiction of inclusive research as a useful umbrella term, extending the participatory and emancipatory research that Walmsley and Johnson (2003) particularly encompassed within it to include research with multiple labels that essentially 'reflect a turn towards the democratization of the research process' (Nind, 2014, 1). This intentionally connects what is going on in the arena of learning/disability studies with that in other arenas in which groups traditionally marginalized - and worse - by academic research are taking more powerful and integral roles in the process of formal knowledge production. In the context of the special issue, I am reflecting on the particularities of research conducted *by*, *with* and *for* people with learning disabilities and its role within the wider contexts covered in the issue.

As I have argued elsewhere (Nind, 2016), a first generation of inclusive researchers have established the need for people with learning disabilities to do research, they have worked out how it could be done and established what essential challenges inclusive researchers face. People have generally done this through a mix of self-advocacy, advocacy and trial and error. Attempts have been made to formalize the research learning involved by providing methods training for disabled collaborators who do not have this grounding (e.g. Strnadova et al, 2014; Garcia Iriate, O'Brien and Chadwick, 2014), but questions have arisen about the wisdom of introducing models of training that re-position people with learning disabilities - whose key contribution comes from their knowledge based on insider, lived experience - into semi-trained researchers in academic likeness (Nind et al., 2015). In this paper I focus on the authentic learning through praxis that has established a sound body of knowledge about inclusive research with people with learning disabilities.

The concept of praxis is strongly associated with Paulo Freire (1970) who argued that liberation for oppressed people can be achieved only by means of the praxis: 'reflection and action upon the world in order to transform it' (p.33). Anwarruddin (2015, 8) reflects on a key feature of Freire's praxis - engaging in dialogue with others - combining it with Gadamer's (2001, 84) notion of praxis as 'making "prudent choices"'. While Anwarruddin is concerned with dialogue between teachers and researchers within locally based interpretive communities, I have more often been working with inclusive researchers in the field of learning disabilities in the same way: to understand what it is we do, reflect on it, and through so doing to enhance the power of the research and the people involved to make a difference to the lives of people with learning disabilities. Thus, praxis in the context of this paper is about making research make impact through 'knowledge communities' (Broekkamp and van Hout-Wolters, 2007) whereby people 'benefit from each other's expertise and thus to generate new knowledges' (Anwarruddin, 2015, 5). Critical in all this is the idea that people with learning disabilities doing inclusive research are not passive providers or consumers of research knowledge but critically engaged in generating it. With this critical engagement Freire's important concept of conscientization comes into play, whereby the involvement in reflection and action fosters new critical awareness of the social reality and transformation of such.

Another key concept in the paper is *phronesis*, which is one of Aristotle's five virtues: the practical wisdom concerned with 'what should I do *now*, in *this* situation, given *these* circumstances, facing *this* particular person, at *this* time' (Schwandt, 2007, 243, italics original). Greenwood and Levin (2005, 51) describe phronesis as 'praxis-oriented knowing', 'the design of action through collaborative knowledge construction with legitimate stakeholders in a problematic situation'. Important in this is different knowledges coming together in new spaces, involving 'an egalitarian engagement across knowledge systems and diverse experiences' (Greenwood and Levin, 2005, 51).

Most inclusive researchers have developed such phronesis, meaning that their knowledge of inclusive research practice is very local, particular and contingent. This practical wisdom from everyday interaction though, when combined with praxis and with *techne* (technical, practical knowledge), supports the understanding of inclusive research as a series of morally-committed, prudent choices rooted in desiring that research is done inclusively and hopefully well (Nind and Vinha, 2014).

A study of the practical wisdom of inclusive researchers

I conceived the research that came to be known as the *Doing research inclusively, doing research well* study (Nind and Vinha, 2012) as a necessary exploration of how far inclusive research with people with learning disabilities in England had come. Prompted by Walmsley and Johnson (2003), I wanted to engage in dialogue with a knowledge community about the thorny, sensitive issues that may not have been discussed or addressed. Additionally, following the lead from Grant and Ramcharan (2007) reflecting on the state of the art of inclusive research, I wanted to a) consolidate our understanding of the practical knowledge about inclusive research we as a community had gained, and b) explore the challenge they highlight regarding 'whether good science and good inclusive research practice can be brought together' (p.12). Rather than departing from praxis and imposing a different kind of knowledge generation on the study, I designed it with Freirean ideas at the forefront, that is, ideas of praxis (action-reflection) and of dialogue as creative and liberating (Nind and Vinha, 2014, 2016). I was intending to stimulate dialogue through which, as a knowledge community, we would revisit our phronesis and see it afresh, thereby creating communal practical wisdom through listening, reflecting and transforming knowledge from the particular to the shared.

The research mechanism was a series of two-hour long focus groups of inclusive researchers (hereafter termed 'participant-researchers' to mark their dual roles as participants in this study and researchers in other studies plus the blurring of boundaries between roles in inclusive research). The need for the people with learning disabilities to be researchers meant that they were more likely to be articulate and politicized than many people with learning disabilities. However, their studies involved a greater diversity of people and we did discuss the challenge of researching with people whose impairments were more profound, such as co-producing narratives and materials through careful responsiveness to nonverbal exchanges. The groups met and re-met three times so that the dialogic spaces were interspersed with reflective spaces. This allowed the research to be responsive to the agendas of participant-researchers and for them to iteratively and actively engage with the data they were generating through their ongoing dialogue (Nind and Vinha, 2016). An additional one-off focus group was held with funders of inclusive research.

Around sixty researchers were involved, recruited through the researchers' networks among the UK communities working in inclusive ways. Some were very established as researchers and collaborations, others were newer to the whole endeavour, but all met the criteria of currently or recently researching an issue of importance for people with learning disabilities. They were selected to reflect a mix of ways of working and to be near enough to each other in the north, west or capital for the practical need to travel to meet. The participant-researchers were organised for the focus groups into a group comprising researchers with learning disabilities who led and conducted their own research, a group of researchers with and without learning disabilities who worked together collaboratively as co-researchers, and a group of academic researchers who used participatory approaches to actively engage people with learning disabilities in research. The groups were relatively homogenous along these dimensions in an attempt to increase feelings of safety and willingness to talk openly in working through points of friction. In my role as focus group moderator though I carefully fed the data and themes from each group in to other groups' discussions. The claims pertaining to what we know about inclusive research generated together in the focus groups

were distilled in the reflective spaces between them through an iterative process of identifying key ideas, strong narratives and critical incidents. The synthesised polyvocal account of the findings was ultimately subject to discussion and checking in a whole-day event involving everyone together in participant validation tasks. The method of incorporating visual stimuli and metaphors to provoke dialogue is discussed in detail elsewhere (Nind and Vinha, 2016), but I argue in this paper that the process of talking together on repeated occasions over a period of several months was important for teasing out and building on the praxis we had accumulated separately and together.

Attending to the ethics of the research meant not just formal approval from University of Southampton School of Education Research Ethics Committee, but considerable time and energy spent making the information and consent materials accessible (a challenge that did not stop when the study began), accrediting the participant-researchers by name in the report to recognise their role in the knowledge generation, and making that report accessible in plain English with illustrations and glossary. Another ethical commitment was to share through open access the findings, case studies of inclusive research and criteria for judging its quality (see Nind and Vinha, 2012).

Learning about doing research inclusively

The particular questions identified in the bid for research funding for the *Doing research inclusively, doing research well* study strongly influenced the direction of focus group discussions and in turn the knowledge generated. These were questions about how people work together as partners doing research, the kinds of things they find out about, the benefits and challenges involved with doing research inclusively, what makes a piece of research good - for people judging it for its research quality and its inclusive qualities, and what could be gained by coming together in dialogue. Important for this paper is how the participant-researchers knew about these things – the authority on which they could contribute to answering them. I therefore outline some of the experiential basis on which participant-researchers were drawing. In doing this I am also pursuing my own ethical duty to acknowledge both the knowledge and the people involved (including the range of contexts) through which the practical wisdom discussed here was accumulated.

The list of knowledge bases is not comprehensive but provides a flavour of the study. Lisa Pointing and Kerrie Ford had been working with Val Williams at the Norah Fry Centre studying personal assistants, building on previous research on friendship and relationships and conducting a study that 'helped people with learning disabilities to really say what research should be done' (Val). The *My Life, My Choice* group were seasoned self-advocates, newer to research but determined to do research that was important in the lives of people with learning disabilities 'to understand what they needed' (Tracey Taylor) such as a recent project on health checks. Becca Cooper from York People First had done research for the National Forum¹ on 'how good our services in the North were for people from BME and newly arrived communities'. The *Better Together, Stronger Together* research team had 'done some training about being a researcher' and research on 'what people knew about advocacy and what people wanted' (Julie Davies). Craig Hart and Ian from Central England People First were particularly experienced researchers, having 'started doing research in 1996' (Ian), partnering with Lancaster University and social research agency BMRB to do the first national survey on the lives of people with learning disabilities. As Ian explained

That meant producing things like consent forms in a different way. Accessible information. Questions which had to be asked in the right manner and right tone. How to ask the questions to a person. But mainly getting the thoughts and the ideas from the people with learning disabilities. But the thing we said first [was] that the questions have to be answered by the person with a learning disability and not by their parent, carer or support person.

There was also a project looking at a self-advocacy group's history (supported by Jan Walmsley) and another looking at Wartime Memories (John Dias and Carlisle People First), a project on parents with learning disabilities and their interactions with social workers (*Change*), a Let's Talk About Sex project (Wigan and Leigh People First) and one on what people with learning disabilities understand about abuse (Joyce Howarth, David Bennett).

There was dynamism in the knowledge journey reflected in the study. The most experienced participant-researchers like Jan Walmsley and Rohss Chapman had been working on doing research inclusively since the late 1980s. By the time of study the roles that participant-researchers with learning disabilities had undertaken were not limited to research (study design, data collection, analysis and dissemination); they were also doing research support roles, involved in partnership board steering groups, educating funding bodies about the accessibility of their tenders, running tenders including judging bids and deciding who gets the money. For most participant-researchers though, some kind of advocacy role remained a primary concern alongside research. The connection with action was never lost, which would have given Freire a reason to be proud! Lou Townson summed this up well from her experience:

Once I started learning about research I just I started asking loads and loads of questions. Why did they do that this way ... Or for example [...] because I had never been in a [long stay hospital] Why were people just sitting around like that? Why were they tied into that chair? Basically just asking questions.

She further explained how intellectual curiosity as well as advocacy underpins their research

one of our other members ... he got talking about history and what it was like for people living in the institutions and he thought it was good for young people to know that. And then we started to wonder what it was like for people there during the war.

Some of the academic participant-researchers had worked in long-stay institutions or as health, education or other service providers. One had been managing resettlement projects and realizing that 'people totally lost their stories', which led her into involving people with learning disabilities in gathering testimonies of their experience (including protest songs) as well as in service evaluations. Sarah Parsons, with a psychology background, found herself rejecting disciplinary norms in favour of prioritizing hearing people's voices, instigated by work with bereaved children. The participant-researchers' routes into doing research inclusively may have been accidental (a 'praxident' – 'praxis plus accident' (Schiera, 2014, 108)), but the desire to do their advocacy, professional and research roles better was driving them. Gordan Grant captured this perfectly:

I think I stumbled into more inclusive forms of research by making mistakes. In the 1980s, quite a long time ago. At that time I was working in Wales leading two research teams and [working on the] All Wales Strategy (1983) which was way ahead of the game ... because it was based on inclusive principles. It requires local authorities to consult with people with learning disabilities about drawing up plans, implementation and monitoring of those plans. So the two research teams read this strategy and were asked to come up with an evaluation plan. And it was only when we were half way down the track I thought to myself: How can we look at a strategy which is absolutely based on inclusive principles, and we're expecting practitioners and policy makers to be drawing people with learning disabilities into their own internal monitoring process - why aren't we doing that ourselves in the way we are doing research. We didn't even consult service users in drawing up our plans. Anyway, the penny dropped in a major way.

Collective wisdom on doing research inclusively

I now summarise some of the collective wisdom from the study. Working in partnership is an area where participant-researchers had been engaging in much reflection in action. How to do this effectively had been the subject of detailed, sometimes painful discussion for research teams as they worked towards generating rules or principles to guide them alongside practical solutions to the challenges in action. Managing the power dynamics when there are researchers from inside and outside the academy with different claims to authority is a fresh and real challenge for each team that does it. Rules about, for example, where research ideas could come from, who could speak, and how decisions were made were sometimes formalized, whereas on other occasions the bonds of shared purpose and friendships got people through this difficult terrain. Our dialogue indicated that *and/both* rather than *either/or* models of thinking were more helpful, epitomized by our finding that 'participant-researchers operated in a very principled way *and* a realistic way rather than just one or the other' (Nind and Vinha, 2012, 28). Similarly, working in partnership meant doing things together (reading, writing talking) *and* doing things separately in tasks allocated according to people's strengths, knowledge or interests. The experience of doing research inclusively forming a 'bridge into new worlds' echoed strongly throughout the focus groups, as did the understanding that talking and preparing could get you so far, but some challenges just had to be worked through 'in the moment' (Nind and Vinha, 2014, 106). While never put in these terms during the focus group discussions, this was praxis - reflection in action, using the practical wisdom gained to push on, to improvise and to learn again and again.

We were able to answer the question of what kinds of knowledge are generated through inclusive research in that there were clearly important topics for research and for which inclusive research was well-suited to exploring: 'knowledge about and for people with learning disabilities, and knowledge that is based on lived experience' (Nind and Vinha, 2012, 33). Participant-researchers discussed what counts as knowledge, recognizing that there are different ways of knowing and that these are not necessarily better or worse than each other. Sometimes inclusive research generated knowledge that was new, authentic and meaningful to those involved in the research but not necessarily new to the body of knowledge in the literature. There are problems in this becoming published research despite its inherent benefits.

The benefits of doing inclusive research came readily to the participant-researchers in their discussions. These included benefits to them in, for example, widening their networks and learning new skills, and benefits to others, with the two often connecting as Kerrie Ford summed up, 'We feel valued and they learn something about us'. Through reflecting on their experience participant-researchers were able to identify the value added by researchers with learning disabilities which centred on their voices, experiences, emotions and cultural knowledge of living with a learning disability, put to use in building rapport in projects, making connections, sharing standpoints, and telling authentic stories with insider authority.

The barriers to do doing inclusive research were equally well understood. Some of these were attitudinal such as inflexible or low expectations on the part of funders. Related social or institutional barriers included universities protecting their territories with obstructive ethics committees and funding formulas. Material barriers were mostly about not having the transport or the monetary stability needed. Participant-researchers had worked on practical solutions to some of these challenges, but many were ongoing. In particular though, they had gained most practical wisdom in addressing the potential barrier of the inaccessibility of information for people with cognitive impairment or limited literacy. This included funding information, ethics and consent information, written data, published literature and complex ideas, theories and language. They had

gained expertise over the years in taking into account individual preferences for how information is presented, allowing time to process information, working with audio rather than written data, visualising concepts and data, co-creating accessible products of research including devising titles that meant something to people and versions of reports in different formats.

The question of how we know whether inclusive research is good research (how good science and good inclusive research practice can be brought together) depended somewhat on each person's standpoint. Participant-researchers with learning disabilities, or who were directly supporting them, particularly valued the relevance of the research as a marker of quality – whether it was meaningful to people with learning disabilities and made their lives better: 'it must ask the right questions' (Carl Bridden). Equally, from this perspective 'it is also about getting the information across' (Durbali Roy). It could only be good if it manages plain accessible language (Becca Cooper). From an academic standpoint quality was marked by good evidence generated through good methods. The research funders also highly valued the quality of the research relationships, requiring involvement of all the co-researchers in 'something that is co-produced' and that 'shapes life beyond the research output' (Emma Stone). Thus, to be good, the practical wisdom is that inclusive research needs to create good knowledge (the research goal), but also contribute to a political (advocacy) goal and a longer term sustainability goal. Working on how to achieve all this was what participant-researchers did and frequently reflected upon. As lead investigators we did not wish to set definitive quality criteria for inclusive research because there was considerable consensus among participant-researchers in support of Val Williams' assertion that 'there is no right way of doing it'. However, we were able to identify from the data and what it said about the priorities and praxis of participant-researchers some questions that researchers wanting to do their research *inclusively and well* would do well to ask themselves:

1. Is the topic relevant to the lives of people with learning disabilities and interesting to them? Could it become relevant?
 2. Does the research involve people with learning disabilities in a meaningful and active way?
 3. Are the participants in the research treated with respect?
 4. Is the research communicated in a way people with learning disabilities can understand and respond to?
 5. Is there honesty and transparency about everyone's role and contribution?
 6. Were the ways of working carefully thought through and adapted in response to needs?
 7. Does the research create worthwhile knowledge?
 8. Are there likely long-term wider benefits for the people involved e.g. new networks, skills, funds, roles, social inclusion?
 9. Are the research questions the kind that inclusive research can best answer?
 10. Does the research reach participants, communities and knowledge that other research could not reach?
 11. Does the research use, and reflect on, the insider cultural knowledge of people with learning disabilities?
 12. Is the research genuine and meaningful?
 13. Will the research make impact that people with learning disabilities value?
- (Nind and Vinha, 2012, 60)

Again, which of these matter most or warrant most discussion will depend on the standpoint of the person(s) doing the reflecting. I suggest that none of these points for reflection can be neglected altogether, but that they can be given varied relative weights permits the necessary variability in how each research team operationalises its goals. We produced the questions from the practical wisdom

of the participant-researchers consolidated as part of their dialogic process. How they are used requires praxis and dialogue on the part of new teams using them. None of us can say that we have stopped learning about doing research inclusively; continued dialogue remains critical to consolidating and developing what we know and understand.

New developments and reflections

The praxis and knowledge discussed in this paper has informed a series of new developments. The work of our new local partnership SPIRITⁱⁱ, which connects inclusive researchers from the University of Southampton with People First Dorset and Choices Advocacy is working with the challenge of doing research that is meaningful and useful to the advocate and academic communities. Those of us involved have agreed to not just identify important issues affecting people with learning disabilities, but to research these topics to see where the gaps in knowledge are, and to try to get research knowledge out to the people who need to hear it including people developing new research project ideas. This will help us in thinking about whether the research is good in terms of what it adds to the body of knowledge internationally as well as locally. In another collaborationⁱⁱⁱ with Barod Community Interest Company colleagues and I are working on the challenge of doing research inclusively when some people are paid to do research and have academic legitimacy while others grapple with losing their disability benefits during short-term periods of payment as researchers or whose contributions before and after funding periods are unfunded and given freely. We are exploring the potential of an online TimeBank for inclusive research in which people with different skills and backgrounds 'give and receive services in exchange for time credits' (Seyfang, 2004, 63). By treating everyone's time as equal a different relationship and new kind of reciprocity should be possible (Cahn, 2004; Nind et al., 2016). To what extent this can disrupt traditional power hierarchies in research is yet to be understood. We need new dialectical interchange between people and between action and reflection to work on this.

I conclude by celebrating the ways of knowing that come with doing research inclusively. Like Greenwood and Levin (2005) I reject the idea that knowledge production is the domain of universities or that some ways of knowing are inherently superior. I have set out to show that people with learning disabilities and their allies researching together are engaging in vital work in 'knowing how' to do this and do it well, that is 'knowing how to act' (Greenwood and Levin, 2005, 51) to reach goals in wise and principled ways. The combination of praxis, techne and phronesis into know-how can and should be passed on across arenas and through time, making a difference to inclusive research and critical conscientiousness more widely. The multidimensional nature of research problems, and the complex political nature of inclusive research, necessitates the generation of practical wisdom with each new study. Importantly though, this can and must accumulate within and between knowledge communities as part of realising the commitment to dialogue as liberating and to transformative research.

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ⁱ <http://www.nationalforum.co.uk/all-about-the-forum/>

ⁱⁱ <https://spiritdisabilityplatform.wordpress.com/launch-event/>

ⁱⁱⁱ <https://wordpress.it-innovation.soton.ac.uk/price-project/>