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Inklusive Forschung

Gemeinsam mit Menschen mit Lernschwierigkeiten forschen

Buchner / Koenig / Schuppener

Inklusive Forschung

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Inklusive Forschung

**Gemeinsam mit Menschen mit
Lernschwierigkeiten forschen**

Inhaltsverzeichnis

2 Forschungsprojekte

3 Kritische Reflexionen und Erweiterungen

Herausforderungen und Barrieren Inklusiver Forschung

Methodologische Reflexionsansätze

4 Inklusive Hochschule

Ausblick

Herausforderungen und Barrieren Inklusiver Forschung

Melanie Nind

Towards a second generation of inclusive research

Summary

In many ways this is a chapter about the point we have reached with inclusive research and where we are going next. The reference in the chapter title to a second generation of inclusive research implies that we are moving into a new phase, or even that there is a step-change on the horizon. I have written elsewhere about the broad spectrum of inclusive research, its evolution, contested nature, and position within important debates and policy shifts (Nind 2014). In this chapter I primarily focus on the inclusive research conducted with, by and for people with learning disabilities. I draw largely on research I conducted in England with inclusive researchers from inside and outside the academy and their allies, supporters and funders and I gratefully acknowledge them. This study, 'Quality and Capacity in Inclusive Research with People with Learning Disabilities', was funded by the Economic and Social Research Council and became known by its more accessible title, 'Doing Research Inclusively, Doing Research Well?'.
I begin with a description of what we might think of as first generation inclusive research with a brief history and look at its achievements. I move on to the calls for standing back and taking stock before moving forward. This includes discussion of the challenges involved in inclusive research and the degree to which these challenges have so far been met. Finally, I build an argument about the characteristics of the next generation of inclusive research, which will reflect a better understanding of its particular contribution and diversity and include greater concern with quality and knowledge – the product as well as the process of research.

1 First generation inclusive research

It could be argued that inclusive research dates back to the naming of it by Walmsley in 2001. The term itself took on greater significance in the important book Inclusive Research with People with Learning Disabilities: Past, Present and Futu-

res (Walmsley & Johnson 2003) where the criteria for inclusive research are suggested and its development discussed. The book not only established a name – an umbrella term – for the various developments going on with people with learning disabilities getting into research, but also the need to think critically about it.

Beyond the academic debate about inclusive research there was a blossoming of research projects involving people with learning disabilities. In the UK developments included:

- local self-advocacy groups being co-opted as researchers with teams of academics;
- some groups arguing the case for doing or leading their own research (Townson et al. 2004; The Learning Disabilities Research Team 2006);
- long-term partnerships and collaborations becoming established (e.g. Carlisle People First Research Team, which included academics and supporters);
- inclusive research becoming embedded in the departments of academics institutions (e.g. Norah Fry Research Centre; St Georges Medical School);
- funding bodies committing to funding research that actively includes those intended to benefit from it (e.g. Joseph Rowntree Foundation);
- government policy interest in inclusive research, including the Department of Health commissioning the Learning Disability Research Initiative (LDRI) in which research had to embrace inclusive principles (Grant & Ramcharan 2007);
- the first national survey being conducted by an inclusive research team (Emerson et al. 2005);
- learning disabled researchers beginning to be involved in reviewing research outputs (British Journal of Learning Disabilities 2012 special issue).

Thus, people with learning disabilities and their contributions to knowledge have come to matter. The Valuing People White Paper (DoH 2001) promoted their active citizenship as people who must enjoy rights, independence, choice and inclusion. In 2001-2003 £2million of Department of Health money went on the LDRI. Similarly in Australia, the government accepted the "view that people with intellectual disability have the right to be involved in issues that affect their lives" (Bigby et al. 2014, 3).

The first generation of inclusive research with people with learning disabilities established the need for people with learning disabilities to do research and how it could be done (e.g. Williams 1999; Abel et al. 2007; Tuffrey-Wijne & Butler 2010). It established what the challenges are (e.g. Stalker 1998; McClimens 2007; Nind & Vinha 2013) and how the research might be communicated inclusively (e.g. Garbutt et al. 2009). Some important findings were generated about the lives of adults with learning disabilities including their histories.

This research developed alongside developments all over the world in participatory action research, participatory rural appraisal, feminist research, participatory health research, decolonizing research and community-based participatory research

(Nind 2014). Concurrent with the developments I have described for the involvement of people with learning disabilities in research, there were developments for people using (or refusing) mental health services (e.g. Beresford & Wallcraft 1997; Schneider 2010), older people (Ross et al. 2005), children and young people (Kellett et al. 2004; Holland et al. 2008), lesbian, gay, bisexual and transgender groups (Browne et al. 2012) and so on. Within and across groups there were people (re-)inventing inclusive research for themselves, over and over again establishing their rationale, arguing their case, working out the practicalities. A multiplicity of overlapping conceptualisations emerged and with this a multiplicity of terms in relation to the research itself and to the people and roles within it.

In the smaller arena of inclusive research with people with learning disabilities there have been attempts to get beyond the conceptual confusion. Bigby et al. (2014: 4) offer the most recent, building on Walmsley & Johnson (2003) to identify three over-arching approaches: (i) where people with intellectual/learning disabilities "act as advisors to researchers, governments and organizations about research agendas, conduct or dissemination of research" (Walmsley & Johnson's 'advisory or reference groups' as the most common model); (ii) where people with intellectual (learning) disabilities act as "leaders or controllers of research" (Walmsley & Johnson's 'beyond co-researching – taking charge'; and (iii) where they act as "collaborators in specific studies with researchers without intellectual disability" (similar to Walmsley & Johnson's 'coresearching'). This illustrates how, to date in inclusive research, concerns have been on roles and team processes as much as the research itself.

2 Calls for a new focus in inclusive research

Questions have begun to be asked about inclusive research. This is primarily in an attempt to enhance rather than undermine its status. Walmsley & Johnson (2003: 12), for instance, reflect on being "troubled by a certain stifling of debate about the real difficulties of including people with learning disabilities in research" and over a decade ago argued it was "time to challenge certain orthodoxies and assumptions in order to clarify what inclusive research is and how and where it can be applied". Aspis (2000, 3) questioned whether "people with learning difficulties are being used as puppets" and Danieli & Woodhams (2004) asked whether participation and emancipation can be de-coupled. I have asked how theorising is done and what happens in inclusive research to people with profound impairment (Nind 2008, 2011). Holland et al. (2008, 1), looking more widely, examined whether participatory research is necessarily "ethically or morally superior" or "more enabling". Similarly broadly focused on children and young people's involvement in research, Greene (2009) and Freeman & Mathison (2009) have raised the issue of the relative importance of the quality of the participation and

the quality of the research itself. Such critical insights lead us away from the now largely answered first base of how/can we research inclusively and toward questions of how can we understand the importance of this, do this better or even know when it is done well.

The most direct reference to a second generation or phase of inclusive research has come from Grant & Ramcharan (2007) when weighing the outcomes of the Department of Health LDRI in the UK and its contribution to both policy and emergent inclusive research practice. They conclude that inclusive research has come to the end of an initial phase in which practical knowledge has been gained. We have also, they say, learned the benefits of inclusive research, in that users of services involved in researching them can:

- offer different perspectives;
- help to ensure that research priorities are important and relevant to them;
- measure outcomes important to them;
- help to recruit their peers for research projects;
- help access hard-to-reach groups;
- assist or control dissemination and use of findings;
- become empowered through taking part;
- become engaged in the politics of service change. (Grant & Ramcharan 2007, 102-3)

Moving forward they point to the ongoing need to better understand the benefits of the experience of inclusive research for those involved and the forms partnership that make inclusive research effective. The "second phase" of inclusive research, they argue, "is more likely to be concerned with outcomes – what kinds of knowledge are attributable to inclusive research and how the knowledge claims of inclusive research can be assessed and authenticated" (p.12). They suggest that we will need to focus on "whether good science and good inclusive research practice can be brought together" (p.12). The challenge for the LDRI project commissioning was that user involvement was an additional criteria and not one that could substitute for "already well-established and robust research that met the canons of science, good ethics and policy relevance" (p. 103). There were no existing standards or guidelines for judging inclusive research for them to refer to and Grant & Ramcharan saw the need for future work to establish quality criteria. In the future they envisioned, it is not enough to simply say that people with learning disabilities are involved in commissioning or conducting research, we need a better cost-benefit analysis, better scrutiny of the ethical implications, and frameworks for assessing the different types of knowledge produced.

3 Taking stock: Doing research inclusively, doing research well

While commissioners of research and the learning disability research community have committed to inclusive research there is still much to learn if inclusive research is to be properly evaluated and regarded as producing sufficient or even best evidence, rather than sitting alongside 'real', quality research as a necessary adjunct. As a methodologist, it seemed to me that addressing the challenge of understanding quality in inclusive research was necessary for inclusive research to succeed as an innovation with longevity sustainable within the mainstream of research (see Wiles et al. 2013). Thus, I sought to mobilise constructive friction in the field and facilitate transformative dialogue (Gergen 2009) by engaging inclusive researchers in scrutinising inclusive research as a 'research problem'. The participants in the new study were to be researchers (participant-researchers) in the task of taking stock of the knowledge they held about their craft, leading to the production of guidance on the issues and challenges, case studies, useful materials, and criteria for quality in inclusive research. The intention was to reach a critical overview. Through this process the realities of a second generation of inclusive research became more knowable.

The research itself was designed to be dialogical rather than inclusive as such. Wegerif (2007, 4), building on the ideas of Bakhtin, argues that "a dialogic space opens up when two or more perspectives are held in tension", thus creative difference opens up the dialogue. However, to avoid the difference being too great, I followed the strategy of Madriz (2000) and Haw (2010) in addressing sensitive challenges about who can speak safely with whom. Thus I conducted a rolling series of focus groups with stable membership of participant-researchers relatively homogenous in their relationship to research (see Nind & Vinha 2012 for details of the methodology). I deliberately moved away from locating authority within individual researchers/researched individuals and instead located it in the interactive space between them. In this chapter I reflect on the findings in relation to the progress and challenges of quality inclusive research, using the emergent themes of:

- identities
- interactions and relationships with each other
- relationships with research and process issues
- relationships with knowledge and product issues.

Identities

Participant-researchers in the study spoke of their identities in ways that indicated their interactions within research teams. Identities related to research included team member, co-researcher, inclusive researcher or advocate for inclusive

research, proper researcher, lead researcher, expert by experience, research supporter, coordinator and advisor. Identities also spoke of current work roles, such as researcher, research assistant, senior research fellow, research student, lecturer, consultant, advocacy support worker or personal assistant, and previous roles thereby indicating transitions and ambivalent status. When identifying themselves by status, participants referred to their role in their organization – self-advocate, trustee, chair, director; whether they were a volunteer, or paid (or even in charge); their (dis)ability and occasionally minority status, for example, as a black person or parent with a learning disability. Sometimes labels were avoided with people preferring to use just their name, or identifying as a team member or human being, and sometimes labels themselves were consciously referred to – a person with a label of learning disabilities. Some participants referred to their multiple identities or to wearing different hats.

Differences between academic researchers and researchers with learning disabilities emerged from the dialogue and these were not restricted to the different roles they might adopt when working together. Other differences included routes into research, experience, pay, career path, roles or titles, skills and knowledge. There were differences (and some commonalities) in terms of what there was to be gained for each party and in what participant-researchers saw as valuable in research, what its impact is on them, and how we see success. Research was seen as more personal for people with learning disabilities where it inevitably overlapped with other advocacy, training and campaigning work.

Interactions and relationships with each other

People's identities influenced how they worked together, sometimes seeking collaboration and sometimes independence, but very often feeling the need to negotiate around the perceived relative power they held. Thus, inclusive researchers don't just get on and research, they negotiate their relationships, taking care to be sensitive to each other's historical and cultural positioning. For example Rohhss commented that in the Carlisle People First Research Team "ideas have to come from members of the group and there's this research cycle we go through". This leads to a discourse of sharing, co-working, and co-analysis that is particular to inclusive research. Lisa talked about how at Norah Fry "we are one big team". Moreover, because the circumstances of the research change, such as whether it is funded and by whom, and because this makes a difference to the identities and discourses, these have to be re-visited time and again. The result is that inclusive researchers often make considerable investments in their collaborative teams or partnerships, often building deep, trustful relationships and sometimes even referring to fellow researchers in the team as friends or a kind of family. Focus group participants who funded and judged research applications looked for wholesome partnerships, shared understanding of inclusive research, and shared purpose,

with one remarking that "this is where you see them [inclusive research partnerships] working best".

Participant researchers, whatever their identity, were conscious of the importance of voice as power. Rules and customs evolved to deal with the sensitivities around power imbalances; for some it was important that ideas came from people with learning disabilities or that supporters needed to practice staying quiet and being in the background. Julie described how she did the method bit of a bid 'but the ideas came from self-advocates'. Narratives of doing inclusive research included narratives of betrayal, transparency, and invisibility. Participant-researchers shared their experiences of who does what in inclusive research, establishing primarily that for them who – is involved, initiates, is in control, makes decisions, makes the rules, asks questions, manages the project, gives information, has input into the report, writes the report, and gets the credit – are all important. These are simultaneously practical and political matters related to who includes who.

We identified a range of ways that inclusive researchers adopted for working together (see Nind & Vinha 2012, 2104). These could be more formalised (pre-planned/rule-bound) or more improvised (responsive). They could involve seeing one group as supporting another, different parties negotiating support and power, or different parties working interdependently such as in one group described as working "as a cooperative" (Chloe). The ways of working usually involved a balance between operating in a very principled way and being pragmatic. The important point for this chapter is that the first generation of inclusive researchers have devoted a lot of their attention to the problems of identity and interaction. While the next generation of inclusive researchers will not be able to skip addressing these altogether, they should require less of their energy as there are models to follow or reject, discussions in the literature to refer to, and groundwork done. The next generation will still be involved in taking risks, learning from mistakes, compromising, adapting, and talking through the challenges, but they will be able to do so in a more informed way. Decisions about the extent to which tasks are divided out according to strengths and resources and the extent to which everyone should do and learn everything will still need to be made, but knowing that these are common challenges may make them less painful and resolving them less effortful.

Relationships with research and process issues

A fundamental finding from bringing inclusive researchers from a range of projects together in dialogue is that there is a variety of ways of doing research inclusively. This may seem obvious but the diversity is important. Different people initiate and get involved, using different partnership models and combinations of paid and unpaid researchers and different research methods.

There were some common features also. Experiences of support were pervasive: practical, emotional, training, peer or mutual support. There was a common focus

on accessibility issues such as making written documents and research methods accessible for all. "Accessible, plain English" suggested by Becca of York People First was valued by many self-advocates, as was "getting the information across" (Durbali) and feedback (Michael). For many participant-researchers a prime indicator of the inclusiveness of the research was the involvement of everyone at every stage. This was the converse of tokenistic involvement. Nonetheless, the bidding and idea formation stage and the analysis and reporting stage both presented real challenges. More experienced participant-researchers with learning disabilities had good understanding of the whole process, some also having personal experience in the role of commissioner/funder.

While accessibility was central to opening up research processes and products to people with learning disabilities, many barriers to involvement in research were identified. Occasional references were made to literacy difficulties as a barrier, but mostly people were reluctant to discuss barriers (other than a lack of curiosity) as existing within the person. Attitudinal barriers though were much discussed and identified as located within funders – their lack of knowledge or understanding, their inflexibility, low expectations and failure to learn or change. Universities were also identified as putting up barriers. Other barriers were about: perceived incapacity "shock horror, these people should be in an institution but they're doing research!" (Kerrie); desire to protect people seen as vulnerable; and limited interest in hearing from people with learning disabilities. Some social process barriers (such as the need to demonstrate research track record) were put up by individual gatekeepers and some were rule-based such as rules about tenders, formal ethics and governance requirements, online submission to journals, need for police checks. Material barriers included people being held back by lack of transport and information, inadequate funding, and rules about receipt of state benefits making short-term paid research risky. It is clear from this research, therefore, that any talk of a second generation of inclusive research should not imply that all the hurdles faced by a first generation of inclusive researchers are sorted.

Relationships with knowledge and product issues

My final overarching theme is about the knowledge and outcomes which inclusive research generates. For those involved in this study this was shaped in part by who would fund them, with the number of funders across around sixty participants limited to twelve. Most of the inclusive research that was done and discussed was about the lives of people with learning disabilities and sometimes about the lives of others as they related to them (support workers, personal assistants, non-disabled people) and about services. The handful of 'other' topics came in studies led by academics. On the whole, researchers with learning disabilities did not do research unconnected to their lives though some indicated some interest in doing so.

The tangible products of inclusive research were diverse, going beyond data, reports, articles, books, conference papers and summaries, to include jointly written articles or co-designed products, exhibitions, plays and poems, films, educational packages, booklets, websites, and national gatherings. In terms of knowledge produced, there were discussions about ways of knowing and what counts as knowledge, with differences across disciplines and pluralities and hierarchies of knowledge coming to light. One group acknowledged that sometimes the knowledge culminating from inclusive research does not add to the body of published knowledge despite being worthwhile to those involved. Discussions illustrated how knowledge for the academy might be different from knowledge 'for us' and 'about us'. Mostly though, the distinctive nature of the knowledge was described as experiential, fundamental, grounded, embodied, authentic or meaningful – using and extending knowledge of the culture of learning disability. Moreover, while occasionally knowledge not related to solving problems and just intrinsically interesting was attractive, mostly the knowledge generated by inclusive research was regarded by participant-researchers as useful knowledge that improves. Examples were found in projects about people with learning disabilities getting into relationships, becoming good parents, and making good use of personal assistants. The outcomes in terms of impacts included not just knowledge and career success, but personal and emotional impact. The impact on the lives of people with learning disabilities was centrally important and this included the personal gains of having raised self-esteem (feeling "valued", Kerrie) and changed horizons and interpersonal gains of making connections with people ("making lots of friends and all that" (John), building bonds and networks and becoming advocates. Long term impacts coded included the research leading on to other projects or roles and continuous/ongoing relationships.

Often talk of the value of inclusive research referred to the value added by the researchers with learning disabilities, such as the voice, experiences, thoughts and feelings of people with learning disabilities, and their cultural knowledge of things like day centres, institutions and personal assistants. Methodologically, some participant-researchers felt that researchers with learning disabilities brought empathy and an ability to create a comfortable feeling for research participants with learning disabilities. They asked more directly relevant questions that were accessible, thus getting better answers and richer data. The inherent authenticity and credibility of inclusive research was stressed, alongside hope that people would listen and take note. There was a desire (based on the best experiences) that inclusive research would itself facilitate inclusion and social change; that organizations would benefit from vital funding coming from research; and (almost incidentally sometimes) that new knowledge would be generated.

Quality in inclusive research was much discussed and different aspects are valued by different groups and individuals, for example some self-advocates valued 'acti-

on not words' and some funders stressed the quality of the partnership. Nonetheless, we were able to envisage from the data that good social science meets good inclusive practice when:

1. The research answers questions we could not otherwise answer, but that are important.
2. The research reaches participants, communities and knowledge, in ways that we could not otherwise access.
3. The research involves using and reflecting on the insider, cultural knowledge of people with learning disabilities
4. The research is authentic (recognised by the people involved)
5. The research makes impact on the lives of people with learning disabilities. (Nind & Vinha 2012, 44)

This list does not replace other quality criteria but rather sums up the contribution of an inclusive approach to the quality of the research and the contribution of quality research to an inclusive agenda.

4 Towards a second generation of inclusive research: ten points of maturation

Inclusive research with people with learning disabilities may have reached a tipping point. By this I refer to the accumulation of knowledge that means that the challenges are now understood, and new inclusive researchers can find guidance on how to research inclusively. But the future of inclusive research with people with learning disabilities is also vulnerable in that it is uncertain where the next generation of learning disabled researchers will come from. This is because the sustainability of self-advocacy groups, where people have largely become equipped to develop as researchers, is threatened by termination of national and local funding. As with self-advocacy itself, the sustainability of inclusive research depends in part on its ability to adapt and evolve. There is a firm foundation in the research evidence to suggest that as we move forward with inclusive research with people with learning disabilities that some territory will be changed as a result of what has gone before. Specifically, there is reason to hope that as this research approach is taken forward in the next decade:

1. Inclusive researchers will not continue to have to justify an inclusive approach.
2. Inclusive researchers will be less preoccupied with our different expertise and, freed from the tyrannies associated with this, we will be more focused on our need to learn from and with each other.
3. We will move on from judging whether we (ourselves and others) are doing it right – following some assumed consensus about the rules – and recognise

instead the diversity of ways in which we might follow the principles valued within this paradigm.

4. Different ways of knowing will be valued and the tensions between them seen as valuable in the search for better understandings.

5. We will recognise that dialogic engagement will not necessarily lead to consensus but to sense-making that is sometimes collaborative and sometimes separate.

6. Different spaces will be made for different kinds of inclusive research and research-related activity (thanks to Anne Collis and Barod (http://www.barod.org/) for this idea). These will be spaces with room to grow; some will be almost typical of advocacy and some will largely replicate (qualitative) research, but some will be distinctive spaces.

7. Bridges between these different spaces will become increasingly established as roles diversify and the value and skills of those people who mediate between research and advocacy are recognised and enhanced.

8. We will recognise the connections we have with inclusive researchers working in other domains and benefit from dialogue with them.

9. We will shift some of our energies regarding process away from negotiating power dynamics and onto matters of the quality of the research, applying quality concepts such as those generated in the research discussed here (Nind & Vinha 2012, 2014) developed for this paradigm.

10. More attention will be paid to the knowledge generated by inclusive research, and we will have stronger, better articulated grounds for arguing its credentials. Inclusive research needs to have something to say about a range of topics that move beyond the research process and perhaps even beyond the intricacies of people's lives.

My vision of a second generation of inclusive research relates to an expansive concept of what inclusive research is and can be. This will be beneficial in that we will be able to celebrate the fluidity and diversity involved in doing research inclusively (Nind & Vinha 2012, 2014). This will hopefully lead to less fear about getting it wrong or failing to achieve everything (Sin & Fong 2010), meaning that we will be better equipped to embrace research with people whose impairments and needs are most profound and complex. Thus, not all inclusive research will be expected to do the vast number of things often expected of it currently (Nind & Vinha 2012, 2014). As we broaden our horizons it is likely that our understandings of inclusive research will be complexified rather than simplified; dialogue should further enrich our reflexivity and criticality in ways that make us better researchers.

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Inklusive Forschung stellt einen Ansatz dar, in dem Menschen mit Lernschwierigkeiten über den gesamten Forschungsprozess hinweg eine aktiv gestaltende Rolle einnehmen. Sie verkörpert somit eine *gemeinsame* Forschung von Menschen mit und ohne akademischen Bildungshintergrund. Während sich dieser Forschungsansatz in den letzten drei Jahrzehnten in vielen englischsprachigen Ländern zunehmend etabliert hat, begann ein vergleichbarer Prozess im deutschsprachigen Raum erst ab den frühen 2000er Jahren – hat aber seitdem eine interessante Entwicklung erfahren, die bislang kaum dokumentiert wurde. Dieses Buch hat daher das Ziel, einen Überblick zu aktuellen und bisherigen Bemühungen im Kontext von Inklusiver Forschung in Deutschland, Österreich und der Schweiz zu geben. Zudem werden hier die gesammelten (Forschungs-)Erfahrungen sowie die damit verbundenen Diskussionen und Herausforderungen kritisch reflektiert.

Zudem finden sich in dieser zweisprachigen HerausgeberInnenschaft Beiträge von VordenkerInnen aus der internationalen Forschungscommunity.

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