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Inclusive research as a site for lifelong learning: Participation in learning communities

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ABSTRACT

This paper explores the learning that goes on when adults with learning disabilities are involved in inclusive (participatory or emancipatory) research. Applying thematic and narrative re-analysis of data from a series of focus groups involving inclusive researchers talking about their research work indicates inclusive research is a rich site for learning. The nature of the new knowledge (know-what and know-how) about the process and products of inclusive research, as well as more transferrable interpersonal learning and development of problem-solving are examined. Participants had, in their involvement in inclusive research, learned to occupy new roles; their narratives are of important and largely enjoyable learning journeys. In an effort to theoretically situate such learning, the paper discusses the fit between the learning evident in the data and concepts of lifelong learning, informal learning, and community learning.

KEYWORDS

Inclusive research; informal learning; lifelong learning; learning community; learning disabilities; participatory research

Introduction

This paper concerns the learning of a particular group of adults, that is people with learning disabilities who are self-advocates involved in conducting research. The context for learning under examination is their involvement in research. This is an inclusive context in the sense of research being a socially valued, mainstream activity, often conducted with non-disabled academic researchers like myself. Together, researchers with and without learning disabilities are learning how to conduct research in new, inclusive ways, that are respectful of the agendas, views and needs of people with learning disabilities (hereafter, termed inclusive research). We are learning how the traditional power dynamics of research can be challenged, what skills we each need, and how we can best work together.

The data for this paper were generated in a study I led on the nature of inclusive research with people with learning disabilities and what constitutes quality within it. The study was conducted in England, over 14 months, and the main findings are published elsewhere (Nind and Vinha 2012) as is a detailed examination of the

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methodology (Nind and Vinha 2014, 2016). The findings about the nature of the learning for the adults involved in the research are a by-product of that study and constitute the focus of this paper. As an educationalist these insights into adult learning in an unusual context prompted a desire to better understand that learning using the concepts of lifelong learning, informal learning and community learning as tools for interpretation. I seek to theoretically position this kind of adult learning with the aim that it might be further fostered.

Background to the key concepts

Adults with learning disabilities are a group who are particularly poorly served by formal education. In the UK these adults have often been sent to special schools, and some have lived in institutions. Despite policy concerns with self-determination and citizenship in the landmark White Paper, *Valuing People* (DH 2007) they may have life stories of being rejected or marginalised and are still to enjoy a good life (Johnson *et al.* 2010). As Wright (2006) argues, further education colleges have offered limited and limiting provision for education. Some adults with learning disabilities have assumed responsibility for their own transformation by joining the new social movement (Bersani 1998) of self-advocacy groups, learning in the context of solidarity to speak up for themselves (Aspis 1997), advocate for their health needs (Feldman *et al.* 2012), tackle oppression and discrimination (Keyes and Brandon 2011), and gain a sense of personal identity (Beart 2005) and expanded social networks (Gilmartin and Slevin 2010). In the absence of other opportunities, Fernandez *et al.* (2002) recognise self-advocacy as having an important role as a site for adult learning. Self-advocates can be viewed as critical investigators of their own situations, concerned with education as liberation not domestication to use Freire's terms (1970), learning not just to make choices as valued by policy-makers (Kaehne 2009), discrete skills taught in transition programmes, or to 'accept the best out of a bad deal' (Aspis 1997, p. 653), but to create choices for themselves.

New found skills in self-advocacy have been put to use by some self-advocates in the conduct of research. Academic researchers in the learning disability field have realised the foolishness of not involving the people who are the objects of their research in more respectful and helpful ways, as people with stories to tell, with advice to give, and who can meaningfully shape and do the research itself. Some self-advocates have argued for their rightful place at the forefront of research about them (Townson *et al.* 2004, The Learning Disabilities Research Team 2006) and some commissioners of research have responded positively (such as with the Learning Disability Research Initiative, Grant and Ramcharan 2007). Over the last two decades the involvement in research of adults with learning disabilities has flourished in the UK (Nind 2011), Ireland (Garcia Iriarte *et al.* 2014), Australia (Bigby *et al.* 2014) and some Nordic countries (Hreinsdóttir and Stefánsdóttir 2010). This research has been ascribed various terms (such as partnership or user-led research and positioned theoretically as participatory or emancipatory research), but inclusive research is now used as an umbrella term encompassing the range of approaches (Nind 2014a). Inclusive research changes the dynamic between researcher and researched such that the research is conducted *with*, *by* and sometimes *for* them, but not *on* them (Nind 2014a). People with learning disabilities occupy new roles as 'instigators of ideas, research designers, interviewers,

data analysts, authors, disseminators and users' (Walmsley and Johnson 2003, p. 10). They are engaged in inclusive research which, by definition, must 'address issues which really matter' to them and the improvement of their lives, 'access and represent their views and experiences' and treat them with respect (Walmsley and Johnson 2003, p. 16).

Becoming an inclusive researcher requires ongoing learning. Understanding the nature of this adult learning requires the introduction of other core concepts. Such ongoing learning might be thought of as lifelong learning, but lifelong learning is an 'elusive' and 'composite' concept with multiple dimensions (Biesta 2006, p. 173) occupying heated political terrain. Billett (2010, p. 401) argues that 'learning is something that humans do' and 'do continuously and across our lives: we are all and have to be lifelong learners'. Such learning is not necessarily dependent on others, but 'directed by our individual needs and intentionality, which are mediated by our capacities and interests and shaped by imperatives and contributions that are external to us' (Billett 2010, p. 401). Billett (2010, p. 402) highlights the learning associated with taking on new roles in life which can involve 'effortful engagement', particularly if it is 'personally transformative'. In this way, lifelong learning is a socio-personal process.

Biesta (2006, p. 175) argues that 'whereas "education" is a relational concept that, in most cases, refers to the interaction between an educator and a student, "learning" denotes something that one can do alone and by oneself'. This individualisation means that lifelong learning has 'become an individual issue and an individual responsibility' (p. 175). For Coffield (1999), this individualisation is problematic, necessitating a 'social theory' of lifelong learning in which learning is located in social participation and dialogue as well as individuals, with reciprocal teaching and learning process which may be informal and implicit. Informal learning thereby 'represents a largely neglected aspect of lifelong learning' with policy and academic discourse focusing much more on formal education and training with targets, courses and qualifications (Coffield 1999, p. 493). Returning to the argument of Billett (2010, p. 402), 'learning occurs in all social settings, not just those setting activities that are directed to particular kinds of intentions' and supported by all kinds of people. Furthermore, the assumption that 'learning arising from activities and interactions in educational institutions is privileged or constitutes the major source of our learning' is unsupported by evidence, and 'there is much knowledge that has to be learnt and not taught' (Billett 2010, p. 403). Without understanding of the informal, argues Billett (2010, p. 410), lifelong learning is narrowly misrepresented such that learning through practice or engagement in communal activity which may give rise to transformative learning gets reduced to 'courses, courses, courses and more courses'. It is rare for the concepts of lifelong, community, formal or informal learning to be discussed in relation to adults with learning disabilities.

Methodology

The research underpinning this paper was originally designed to build knowledge and capacity in inclusive research with people with learning disabilities, to take stock of the knowledge base, produce guidance on the issues and challenges, develop materials and case studies, and produce criteria for quality in inclusive research. A focus group

design was devised to create vibrant interactive spaces for inclusive researchers to share and develop their knowledge thereby using dialogue to work at exposing the reality of inclusive research and knowing it afresh. In this way, the research was designed to be educational for everyone involved in discussing what it means to do research, do it inclusively, and do it well.

There were 66 participants who were recruited through existing networking and a snowballing approach. They varied in the extent of their experience from pioneers of inclusive research to relative novices; their relationships with the academy also varied. Most were qualitative in orientation. The research design was a rolling series of encounters in focus groups of around ten people; the dialogic spaces of the focus groups were interspersed with reflective spaces of analysis (see Nind and Vinha 2016). Two focus group communities comprised researchers with learning disabilities conducting their own research; one comprised researchers with and without learning disabilities working collaboratively; and one comprised academic researchers using participatory methods or design to include children or adults with learning disabilities. Their relative homogeneity was intended to bring a level of safety to the groups to enable them to 'grapple honestly' with sensitive questions (Walmsley and Johnson 2003, p. 16). These focus group communities each met up to three times with increasing rapport. Walmsley and Johnson (2003, p. 12) note a 'certain stifling of debate' about the real challenges of inclusive research and Grant and Ramcharan (2007) conclude that having gained practical knowledge of inclusive research, there is a need to establish the kinds and quality of knowledge attributable to it. Thus, the line of questioning pursued the real, lived nature of working in partnership, the kinds of knowledge generated, how quality in both research and inclusion is recognised, and what new knowledge could be gleaned from sharing and interrogating practice. An additional focus group interview was also conducted with a small group of funders of inclusive research and a plenary session brought participants together to inform the final analysis. The research design did not involve participants being actively engaged in every stage of the research process, but it was participatory and respectful in the sense of being built around dialogue. Participants largely wished to be named and credited as co-constructors of knowledge generated; this is something I respect in this paper and had ethics approval for from University of Southampton.

The focus group data were analysed using a 'range of interconnected interpretive practices' to 'get a better understanding', each practice making 'the world visible in a different way' (Denzin and Lincoln 2005, p. 4). Thus I engaged in a process of coding themes alongside identifying core narratives, thereby ordering experience without reducing people's lives and stories to data in an objectifying way (Nind and Vinha 2016). This interpretative process generated models of ways of working in inclusive research and ways of understanding quality in inclusive research as originally intended (see Nind and Vinha 2012, 2014). I have since returned to the dataset to shift my analytical lens from the methodological to the educational. Transcripts of twelve focus group discussions and accompanying fieldnotes were re-analysed, to specifically elicit themes and narratives about the learning involved in inclusive research; this was done without any *a priori* hypotheses beyond the sense that participants were aware of learning going on. I have related the themes back to the wider literature to consider

inclusive research as a site of learning for adults with learning disabilities (and their allies and research partners) and to explore the nature of that learning.

Findings

Firstly, I present data that illuminate the dialogue pertaining to adults learning. This includes the focus of the learning, the learning process, and narratives of learning journeys. Secondly, I further interrogate this learning using the concepts of lifelong, community, and informal learning.

For the participating researchers, learning in the context of doing inclusive research encompassed overlapping skills-based learning related to research (know-how) and methodological knowledge about the nature of (inclusive) research (know-what). Added to this was learning about the rules of the game (what it means to be an inclusive researcher); interpersonal learning (often related to new roles); and problem-solving (such as how to make methods accessible).

In terms of learning research skills, learning disabled participant-researchers in particular learned much about data collection, especially conducting interviews. Malcolm, a self-advocate who had gained experience in a research cooperative of self-advocates, supporters and academics, described the interview and his accumulation of know-how and confidence: ‘When you are interviewing you got to look in the eyes, the mouth, the lips and the eye contact as well. ... They say it’s very hard but it’s not, when you get used to it, it’s not that hard’. Similarly, self-advocate researcher Becca commented on what, in her experience, makes a good interviewer: ‘listening skills and good support workers to take notes so that you remember what you saying’. People learned from good experiences such as the first national survey of the lives of people with learning disabilities, described by self-advocate Ian as ‘probably the most successful research project we [our self-advocacy group] have taken on board’. But there was learning arising from less successful work too, with Becca learning the lesson of poor response rate faced by many novice survey researchers.

Some of the learned know-how related to data analysis. Lou, an experienced self-advocate researcher from the research cooperative described learning various roles in the analytic process including related to field-notes and transcription. She described the learning process her group went through:

What we did with analysis was, we used to transcribe all the tapes I actually did some of that. But then we realised that ... some people in our research group can’t read so what’s the use of transcript in word form when you could just listen to them as tapes. So we went through the tapes using flipcharts around the room and people would pick themes that came up. It was not one of those like right we’ve analysed it that’s it, we kept adding to it. So we did copies of tapes for people so they could bring home and listen to it at their leisure. ... People would say things like funding, and we [would] see that as a theme.

Some of the learning process for this shared analysis (referred to by some participants as co-analysis) was reconstructed through the process of dialogue between self-advocates, and between self-advocates and support workers: Self-advocate Craig described a process of talking and ‘looking at stories’ and Becca explained analysis to a peer as ‘looking at meaning’. Kelley, who had been immersed in inclusive research as

an academic, had learned to see analysis and theory development for self-advocates in terms of ‘the stuff that is important to them’, ‘what they’ve learned from what they’ve done’. Extending beyond specific skills, the know-how related to the research process as a whole and how it gets started and is managed ethically. The participant-researchers also volunteered a lot about their learning experiences related to the skill of disseminating research, including talking about ‘my first international research conference with over 1000 researchers’ which ‘was quite a daunting experience’ (Ian), report-writing – ‘how we did the research and how we put it on the internet’/‘how we deliver the story’ (Craig), uploading video on YouTube (Michael), and using dance (Sharon) and drama (Becca) to communicate the findings.

Experienced self-advocate researchers talked a bit about *how* they learned their craft. For example, Lou explained that ‘Once I started learning about research I just I started asking loads and loads of questions’. Ian reflected on applying his skills ‘working quite hard to support people to manage it [research] themselves’. When asked how she learned about the research process (training or on the job) Rose confirmed, ‘I learned on the job’ and Kerrie shared the benefit of her own learning through experience, in part reprimanding other practice including mine:

It’s ok people sending consent forms, but one thing that I learned is that before you send out the consent forms, what you should do, you should make yourself, get up off your backside and go and see the people that you are going to send the consent forms to, take a copy of the consent forms that you have got and then see if it matches to what they would find easy in a consent form.

She expanded on how she learned about this:

I learned about doing it through working with Lisa [another researcher with learning disabilities] one day. We were sent off with Val [academic], I think it was, to do a research project in York. We took up a consent form and they didn’t understand it. So we thought, I don’t know if Lisa can remember that. So we thought how can we make the consent forms better?

These adult learners spoke with understated pride about what they had come to know, realising that ‘everyone doesn’t understand what research is’ (Elizabeth). In one focus group self-advocate researchers spent time discussing what makes research inclusive, using the metaphorical device: *if inclusion were a cake what would the ingredients be?* This was something the group had come to know, with ingredients contributed including ‘the topic we’re going to research’ (Becca) which had to be relevant (Carl) ‘to us’ (Becca and Carl). ‘The jam is going to be us, because we’re in the middle of the cake’, Carl asserted. Becca focused on the accessibility, suggesting vital ingredients were ‘translators’, ‘money’, ‘accessible buildings’ and ‘partners’, and Durbali chipped in that ‘everybody has to be involved’. Carl’s experiences had taught him that the ingredients vary across projects ‘one time you can [do] one thing, sometimes you put something else in your cake ... Different. Possibly, you make the same cake and it turns [out] different’. The data showed that this was nuanced rather than formulaic learning.

There was also evidence of learning that research is a kind of game with rules. Lou talked about their group having transcribed interviews ‘for the sake of it’, not for their analysis but because funders expect it. An experienced academic wanted to check if their assumption was correct ‘did they [funders] ask to see the transcripts?’ (Jan), but

the support worker confirmed that they hadn't, showing that she too was in the process of learning the rules of the game. They were playing the game of participant validation too, sending out transcripts to participants who they knew were unable to read them merely because they felt that they should. The learning continued into the focus group itself as another experienced researcher pointed out that the participants might, nonetheless, value having the record of the interview. In another example Carl showed his learned awareness of the power of specialist language in research, arguing that the term 'inclusive researcher' 'sounds better, it makes you look clever'. The more experienced researchers with learning disabilities had learned how to work with their funders while for more novice researchers aspects of the funding world were a mystery best left to the university and support people.

Inclusive research, though, was a site for interpersonal learning for the academics and support workers as well as for those with learning disabilities. Academics talked about learning the limitations of research that is not inclusive and having to learn new approaches and roles as they take on 'multiple identities' (Gordon) of researcher, co-researcher, and co-worker. This was an ongoing process spoken about in terms of 'you're always learning' (Sarah) and 'co-learning' (Will). The support staff had not always chosen to learn to do research but had to as there was pressure for self-advocacy groups to get involved in research partly because 'this is how we get money' (Catherine). Karen, who supported one individual commented, 'research is new for me' and observed that she had learned research skills alongside the self-advocates.

On several occasions the dialogue turned to learning to work in new teams and new ways. Ian, a self-advocate who had worked on the national survey in collaboration with academics and market researchers, reflected on 'How we worked together was going to be completely new to our partners as it was to us because all partners work in different [ways] so ... We sat down and worked out the best way of doing it'. Ian's group told another narrative about learning new roles, co-constructed with their academic partner, Jan. A group with learning disabilities conducting research on employment described their different, chosen roles, one transcribing, one making easy read (accessible) versions, and two doing data analysis. Gareth described his team of self-advocate researchers learning together: 'Kerrie and Lisa help each other, they will talk about the project together, then Lisa will talk to somebody else and Kerrie to somebody else and then the word is spreading out and then come back together and you have your project.'

The data include several narratives of learning journeys. Lou explained how over time her 'skills have moved from researcher to researcher support.' She and Kerrie had moved into some university lecturing, including 'teaching people about how to do research' (Kerrie). Gordon (academic researcher) talked of having 'stumbled into more inclusive forms of research by making mistakes'; realising that the inclusive principles which informed other aspects of his work also had to apply to research was a moment when 'the penny dropped in a major way'. For the people with learning disabilities though, the initiation was into research itself, starting from 'I didn't know what research was' (Lisa). Lou recounted, 'I got into doing research [when] I was looking into the local day service closing down and what people thought of it. Back then I didn't even know that was what we were doing, I thought research was just what the professionals did ...'

Most of the steep learning curve narratives of self-advocates were very positive. Malcolm spoke of ‘a lot of enjoyment’ and Susan observed, ‘I want to do it again because I like doing it’. One group of people with learning disabilities mostly leading their own research discussed the satisfaction they got out of doing research and being good at it; with their learning came gains in confidence and ‘sense of worth’ (Kerrie). There was also recognition of some of the tedium of transcription, though it was some of the support staff who presented narratives of graft. In this sense for some participants inclusive research was a site of struggle as well as enjoyment and learning.

Making sense of inclusive research as a site for adult learning

I have shown how parts of the focus group discussion data depict inclusive research as a rich site for adult learning. I now examine further how the nature of this learning might be better understood, firstly as lifelong learning.

Biesta (2006) depicts a multi-dimensional model of lifelong learning evident in most policies with the dimensions spanning the economic, personal and democratic: The (now dominant) economic dimension concerns ‘the acquisition of new skills and knowledge in relation to the world of work ... important both for one’s own employability and financial well-being and for the well-being of the economy as a whole’ (p. 173). The personal dimension concerns ‘developing one’s potential and talents’, ‘finding the “meaning” of one’s life, and maybe even learning to live one’s life in a better way’ (p. 173). The democratic dimension is about ‘the empowerment and emancipation of individuals so that they become able to live their lives with others in more democratic, just and inclusive ways’ which is ‘important for the well-being of individuals but for the quality of democratic life itself as well’ (p. 173). The data suggest lifelong learning in action across these multiple dimensions.

There were, amongst the data, echoes of the economic dimension of lifelong learning, of *learning to be productive and employable* (Coffield 1999), learning to operate in a market place necessitating competing for research money. Coffield (1999, p. 483) argues that

if people are to be treated first and foremost in relation to their potential contribution to the economy, then a market value is attached to each individual according to that contribution. So people with learning difficulties may come to be seen as a poor investment, more expensive to train, less flexible and less employable.

Yet inclusive research is a site where people with learning disabilities are needed and valued for their insider cultural knowledge or expertise by experience of what it is to be learning disabled. The self-advocate inclusive researchers were not so much gaining power as consumers (Crowther 2004) but as people with valued human capital. This changed the market and provided an opportunity for many of the participants with learning disabilities to gain paid work in addition to enjoying the social experience of doing research. These researchers were learning the rules of this game, including something of the inherent structural inequalities when their careers as researchers did not progress. Their reason for doing research was a mix of intrinsic interest and concern for the survival of the self-advocacy group and the well-being of people with

learning disabilities. The learning was largely self-directed but sometimes of economic necessity.

The personal learning for the researchers with learning disabilities, the *learning to be* (Faure *et al.* 1972) or ‘process of becoming’ (Freire 1970, p. 84), was somewhat of a natural extension of their self-advocacy. The learning was strongly anchored around asking questions and talking things through which echoes Freire’s (1970) argument that dialogue is the process for collective learning. The personal dimension was evident in the often referred to sense of individual self-fulfilment, alongside a sense of continuous and conscious learning in adapting to new roles and challenging situations. There were echoes of Billett’s (2010) lifelong learning as a socio-personal process mediated by a new situation demanding new knowledge and skills. There was evidence, too, of his quality of ‘effortful engagement’ (p. 402) – in this case in research worlds that took people to expansive new experiences such as speaking at conferences and gaining public recognition. The dynamics of the group discussions in themselves lay bare the personal and interpersonal learning as participants questioned and probed, chimed and challenged, prompted and mediated.

In terms of the democratic dimension of lifelong learning these adult learners were learning new roles for a common good. Learning to be an inclusive researcher was not an individual responsibility of the kind lamented by Coffield (1999), Mayo (2013) and others as depicting many models of lifelong learning. Instead it was a group responsibility. Their learning was with each other and for each other. Mayo (2013, p. 36) endorses the theoretical stance of Dewey and Freire that learning for democracy and citizenship necessitates ‘engaging in a democratic learning experience governed by non-hierarchical social relations’. Similarly, Biesta (2006, p. 178) sums up democracy as being ‘about learning from difference and learning to live with others who are not like us’, meaning that ‘democracy can only be learned *from* life’. The participants were researchers from inside and outside the academy, they were people with and without learning disabilities and with and without formal research training or salaries, and within inclusive research they were learning together across difference. Riddell *et al.* (1999, p. 447) argue that earlier (UK Conservative) reform of the public sector was based on a notion of ‘citizenship rooted in individual rather than collective empowerment’, unlikely to be helpful for ‘those who lack information and power to act autonomously, such as people with learning difficulties’. But these data suggest collective empowerment and democratic lifelong learning in combined action to gain information.

Edwards *et al.* (2002, p. 532) assert that: ‘Any understanding of learning that is life-long and life-wide requires analysis of the learning that takes place outside of as well as inside institutionalized, accredited participation in formal education and training’. For Livingstone (2001, p. 2) what distinguishes formal education is the presence of a teacher with ‘the authority to determine that people designated as requiring knowledge effectively learn a curriculum taken from a pre-established body of knowledge’. Informal learning, in contrast, is often associated with practical knowledge which is more tacit in nature, and with self-directed learning. Informal learning is often tacit, perpetual and irregular in time and space, hence it is considerably under-estimated and under-researched. This may help to explain why the learning that goes on in inclusive research (and indeed in self-advocacy groups) has rarely been examined in this way

before. Yet the data indicate inclusive research as a site for lifelong learning of the kind that is informal. There is no prescribed curriculum or designated teacher and in place of this the experience becomes the teacher as these researchers learn through their activity as researchers. Amongst the dialogue there was evidence of informal mentoring, of learning to take on supporting and teaching roles, and of learning from mistakes. Support workers were learning as they went along too, keeping a few steps ahead so they could perform their mediation and support roles. Billett (2010, p. 403) reminds us that 'there is much knowledge that has to be learnt and not taught'. While some formal learning may have been helpful and is often called for (e.g. Johnson 2009, Garcia Iriate *et al.* 2014), for the self-advocate and academic researchers participating in this study their involvement in inclusive research evidently provided for some intense or transformational learning experiences.

In making sense of the data generated on adult learning in the context of inclusive research, it is also useful to invoke the concept of community learning, which is an altogether more elusive concept. Falk and Harrison (1998, p. 613) maintain that community learning is 'often misrepresented only as the learning of individuals within a community'. They prefer to see it in terms of community members contributing to a group outcome and group knowledge. Communities are 'individually and collectively ... continually increasing their capacity to produce the results they really care about' (Topolsky 1997, p. 3, cited by Falk and Harrison 1998, pp. 613–614). Thus, a learning community is a 'specific community where learning is continuous and transforming' and 'community learning' is 'those individual and group processes which not only produce, but also *sustain* community development outcomes' (p. 614). This is highly pertinent to the involvement of self-advocacy groups in inclusive research and adds an important set of overlapping concepts to the interpretation process.

The data certainly indicate that various participants were involved in learning as a group and that groups were being sustained through the focus and practical funding that doing research brought. Billett (2010) cites Giddens (1991) in positioning lifelong learning as being about 'the remaking and transformation of the society in which we live'. The participants and I are clear that the society in which we live is a disabling one and we share a collective concern with addressing disabling barriers. While Billett (2010, p. 407) sees education as 'an institutional fact' and learning as a 'personal fact', I can also see it here as a community fact. The learning has a point for the individual, but the context of the research group or self-advocacy organization and the wider group of people with learning disabilities is important. This is the collective learning within a community of actors that Foley (1999) refers to. The struggle that the lifelong learner is caught up in is, Biesta (2006, p. 177) argues, 'over what counts as "real" or "worthwhile" learning'. This is problematic when lifelong learning is seen as a 'private good', but this community of learners (by which I mean this social unit with ideas and activity in common to connect them) values highly what they do collectively, and their knowledge and learning is increasingly being valued by others.

Falk and Harrison (1998, p. 610) refer to the crucial community learning processes in learning communities which result in 'the accumulation of social capital' by those communities. The communities represented in this project were bound by similar purposes and concerns with better lives for disabled people. That individuals like Ian, Lou and Kerrie gained social capital as well as skills and knowledge is evident in the data.

This was transformative learning. The overall capacity for inclusive research though was, in my reading of the data, more communal than individual. The NIACE (2014) report on the outcomes of the UK Community Learning Innovation Fund (CLIF) projects (as part of the government's Community Learning Reform programme) shows outcomes which have parallels with outcomes for the researchers with learning disabilities in this study. These include increased agency and 'progression to further learning, other social relationships, employability and mental health' (NAICE 2014, p. 7). NIACE argue their robust evidence concerning their projects shows that community learning is transformational for people and organizations. Many of the factors seen as leading to success in CLIF projects were in place for the participants in the inclusive research study too, particularly their activity being 'learner-centred', 'grounded in community needs and interests' with 'committed and effective project managers' and 'fruitful partnerships' (p. 10).

Learning for community is about 'learning that promotes social renewal and strengthens communities by raising the sense of possibility and aspiration of individuals and groups to get involved in and improve their communities through active citizenship, community participation and/or volunteering' (NIACE 2014, p. 22). This is the kind of capacity-building described by Falk and Harrison (1998, p. 612) which involves learning and applying that learning to use in a sustainable way: 'The capacity of the community is said to be the combined influence of a community's commitment, resources and skills that can be deployed to build on community strengths and address community problems and opportunities'. This reflects well what was recounted in the focus groups as happening in the self-advocacy groups and research collaborations, which was for mutual benefit and involved developing their capacity to produce outcomes that matter to them. In that their learning was transforming and sustaining it can be understood as taking place in learning communities. Inclusive research team meetings were presented as places for sharing ideas and visions, working together in shared and distributed tasks and roles, involving community members and leading to public accounts and passing on of skills and roles. These are all characteristics of learning communities developed by Brooks and Moore (1997) and used by Falk and Harrison. Some of the participating self-advocate researchers were even quite evangelistic about the need for momentum: as Lou puts it, 'we need experienced researchers but how are we supposed to get experience if nobody will give [us] a chance to actually do it'. The data illustrate the theoretical argument that capacity is not fixed or located in individuals but distributed (Goodley 2001). The dialogue did not capture the 'distance travelled' (NIACE 2014, p. 49) in the explicit way the NIACE research did, but it often communicated a sense of this together with the power of community learning to change lives for the better.

Conclusion

Based on analysis of the dialogue with a range of inclusive researchers and applying conceptual tools from adult learning literature, I conclude that it is important that inclusive research be understood as a site of lifelong, informal, community learning. This holds true for the different partners involved in inclusive research collaborations, but it is particularly pertinent for the adults with learning disabilities whose

opportunities for such learning often emerge from, and then extend beyond, their involvement with self-advocacy organizations. Both self-advocacy and inclusive research can be regarded as social justice-oriented social movements and thereby learning sites (Welton 1993). The informal learning involved in inclusive research can perform the role of supporting sense-making of experience of the world and how to improve it. Informal learning happens especially when our lives and roles change (Billet 2010) and involvement in inclusive research has particular value for self-advocates in this respect as I have shown. Edwards *et al.* (2002, p. 527), in attempting to helpfully theorise lifelong learning, argue that ‘learning itself needs to become reflexive, to be part of the “life politics” of individuals, organizations and societies’; bearing in mind that ‘particular social and cultural conditions’ (p. 534) are needed for this, it is entirely compatible with learning in the context of self-advocacy and inclusive research. The people involved with this are, vitally, a part of that context and should not be seen as separate from it or located within it; they are crucial to the context, which is, as Fenwick (2001, p. 21) argues, so much more than a ‘container’ for experience.

When Virginia Woolf, in *A Room of One’s Own*, considers how she should talk about ‘women and fiction’ she mulls that this might

mean women and what they are like; or it might mean women and the fiction that they write; or it might mean women and the fiction that is written about them; or it might mean that somehow all three are inextricably mixed together (Woolf 1928, p. 5).

I have been through a similar mulling in considering how I should write about inclusive research and learning. As part of the work to instigate the study discussed in this paper I stressed in the grant application that this would be about building capacity for inclusive research by sharing understandings, taking stock and thereby developing deeper insights as well as practical guidance. I have since looked at inclusive research and inclusive education together, and I have argued that they should come together more often than they do (Nind 2014b). And, in this paper, I bring together inclusive research and learning in a different way, following the data to see where they lead in terms of what I can say about inclusive research as a site for learning. To go beyond the original specified research intentions in a kind of solo secondary or re-analysis of the data in this way is risky from the perspective of the research dynamics that inclusive researchers value. Yet following one’s instincts through the data is also what qualitative researchers do. I have pursued this line of analysis because, firstly, not venturing further into this ‘non accessible space’ (Bigby *et al.* 2014, p. 9) would be to restrict my own learning, and secondly, because these projects, like Woolf’s, are inextricably mixed or linked. To understand inclusive research better, so that it might be applied toward social justice goals like making education more inclusive, involves understanding its potential for learning. In this paper I have theorised the learning that can be teased from the data, which is important for future work on the opportunities and threats afforded by formal training in inclusive research. I suggest that to rush further into advancing ‘training’ people as (inclusive) researchers without robust reflection on the learning that might be trampled over in the process is foolhardy. There might be value in resisting regulating or managing these learning experiences and the identities shaped by and shaping them (Michelson 1999). Perhaps the educational role is not to formalise the learning but to support meaningful participation in the learning site (Lave and

Wenger 1991, Fenwick 2001). It is my hope that working with data and ideas as I have done in this paper will foster reflection rather than unquestioning aspiration for the social and educational good that might come from an inclusive methodological stance and an assumed research training to support it.

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