**Introduction**

Most adults are able to take some control over where they live, to make decisions over where exactly they dwell and, as a consequence, to reflect upon their own locational histories[i]. Their residential decisions will be made autonomously or in conjunction with significant others, with the mere mention of home inspiring vivid accounts of those places in which they have lived and worked, the reasons behind their moves or non-moves, and maybe even including intimations of those places that they might aspire to occupy in the future. For some adults, however, most notably those with learning disabilities[ii], these life decisions are partially, if not wholly, made on their behalf; it is therefore the aim of this research to uncover more about what decision-making opportunities are afforded to people with learning disabilities (PWLD) and latterly how their role or non-role in this respect impacts on their feelings about 'home'. By embracing learning disabled lives, this paper seeks to challenge the role of 'expert' in my research, identifying the need for a sensitive co-production of knowledge regarding home-space which recognises the importance of alternative methods of communication and participation in research. Utilising a specific suite of methods which look to probe the mundane, yet in various ways profound, realities of living with a learning disability, this paper seeks to blur the distinction between researched and researcher, allowing the voice of PWLD clearly to be heard. Indeed, geographers such as Chappell (2000) and Hall (2004) have questioned the integrity of research which fails to allow PWLD to control at least some part of the process. The paper begins then, with a discussion on how PWLD have come to be seen both socially and within the research process, moving on to think more deeply about how disability can be considered within co-productive geographical research. From here, it is pertinent to discuss those historical legacies from which the current ethics and politics of

disability research have grown. Finally, the paper turns to a discussion of the experience of designing and conducting a co-produced piece of research with PWLD.

## Recognising disability in geographical research

Historically, PWLD have had few opportunities to contribute to decision-making, something too often reflected within the environment of research involving those with learning disabilities. Jurkowski (2008,1) argues that within research PWLD are more often employed as 'subjects' rather than engaged within the process of creating, carrying-out and disseminating study material. Yet over the years, changes in epistemological approaches have opened new ways of tackling learning disability research. Goodley (2001,208) has spoken of bringing intellectual impairment out of its "uncomfortable and counter-productive exile" as a problematic feature of the medical model of disability, so allowing the methodological freedom to acknowledge the individuality of impairment. This move, in turn, allows researchers to mould methods which speak to the abilities of the participant, creating a less prescriptive environment for the co-production of research about learning disabled lives. Walmsley (2004) suggests that through support of 'inclusive' research, work can be co-created in order best to reflect the lived experience of being considered learning disabled. To allow this to happen effectively, Clements et al (1999, 110) claim that researchers and academics "need to learn better communication skills". Aldridge (2007) argues that unwillingness by researchers to step out of the conventional models of research will continue to marginalise PWLD, and Gilbert (2004, 273) suggests that an increase in collaborative methods of research construction and dissemination can open "a new discourse of participation".

McClimens (2007) posits that current thinking has moved on not only to consider who should be involved in the research process, but also *how* they should be involved, something which MacPherson et al problematised in 2014. Though clearly not a new issue, renewed calls such as MacPherson's for more inclusive, co-produced research in this field suggest that it remains a pertinent focus within disability research, bringing with it a new set of challenges to be discussed in this paper. Adopting new communication strategies, while undertaking research *with* as opposed to *on* those with learning disabilities, offers much to those with learning disabilities taking part in the research, but the ethical complexities presented when trying to create research with vulnerable groups cannot go without mention. Further difficulty is added when committing to this form of research in the constraints of the PhD timescale, undeniably impacting on how truly co-produced research is able to be.

Politics in Disability Research

Nind (2008, 4) suggests that an overall research design involving PWLD should be based on a thorough questioning of whether research is "for, with or on" PWLD, a construction echoed by Kitchin (2001) in his discussion of geographies of disability more specifically. Power relations between researcher and researched can be unbalanced, and Nind (2008) argues that this problematic is furthered by traditional qualitative research which tends to treat the 'subject' of the study as a homogenous group. Furthermore, Ware (2004) suggests that work *on* PWLD, which does not include or consult them at any stage of the research process, runs the risk of appearing incomplete. Drawing from early sociological qualitative work, Kiernan (1999, 44) suggests that research should be "cooperative experiential inquiry" where research 'subjects' become co-researchers. This challenge over who should "own and direct" research is essentially political, with Swain et al (1999) arguing that learning disability research has

exploitative potential.  Gilbert (2004,298) suggests that the "attitudes of professionals, the diversity and complexity of lay groups, knowledge, power relationships, resources (both personal and financial), and values" continue to impact on the representation of PWLD throughout the research process, arguing that, instead, a move away from "protectionism" would allow a recognition of the "empowering potential" of research which involves PWLD. These protectionist attitudes are not unwarranted and have been constructed amid well-placed fear for the safety of those with learning (and other) disabilities within any research process.

Participation, emancipation and co-production

Drawing parallels with the feminist stance on biological sex vs. gender, Shakespeare (2006, 197) argues that, like gender, disability could be considered a "historically specific phenomenon, not a universal and unchanging essence"; and so, methodologically, it is important to approach research with PWLD with an open and flexible suite of methods which recognise the possible implications, both positive and negative, for those who take part in the research.

Within rights-aware learning disability research, two loosely competing paradigms have emerged, each seeking to conduct and create research which is both fair and accessible, but with significant differing emphases: on the one hand, participatory research and, on the other, emancipatory research. Gilbert (2004, 299) notes that each "promote[s] a particular philosophical or ethical position", each aiming further to understand the relationship between PWLD, others and their environments.  Both of these perspectives are socially motivated, but in this context participatory research is (perhaps surprisingly) critiqued for clinging to 'normative ideals', whereby difference is seen as deviance, and so is maintained

within an ongoing cycle of stigma and social exclusion[iii]. Emancipatory research is said to be drawn from the social model of disability and, as such, aims to catalyse political change through the research process. Essentially, Gilbert (2004, 300) argues that the distinction between participatory and emancipatory research lies in the decision over who is in control of the research process. Through participatory approaches, the researcher collaborates with participants using qualitative methods which extract answers to a specific question set by the researcher. Conversely, emancipatory research allows participants to use the expertise of the researcher to initiate research in areas of importance to them, effectively changing the relationship between researcher and researched. In this guise, emancipatory research is positioned as necessarily co-productive.

Atkinson (1997, 17) points out that, while control of the research process for PWLD is an ideal, the reality of achieving this is less likely considering that participants may have "little or no access to either the written or spoken word", and so suggests instead an alliance between PWLD and "sympathetic non-learning-disabled people" around them. While both methodological approaches could be considered distinct, Stalker (1998:6,) suggests that they share three core beliefs: recognition of the researcher/researched power imbalance; the right of PWLD to be consulted and included in research which discusses them; the ability of participation by PWLD to strengthen the research process and make outputs more relevant. Gilbert suggests that this core then highlights a bridging point between each approach, whereby some aspects of each might be usefully employed within research with PWLD. Moreover, Walmsley (2004) suggests that, through support of 'inclusive' research methods which work between emancipatory and participatory approaches, research can be co-produced in order best to reflect the lived experience of being considered learning disabled.

In effect then, I arrive at a sense of wishing to combine participatory and emancipatory approaches, arguably much like most geographers working along these lines in other fields. Hence, my specific claim is that the apparent divide between participatory and emancipatory approaches, sometimes identified in social learning disability research, can usefully be bridged by adopting the geographers' push to be co-productive researchers. This push to be more co-productive, however, can be interrupted by the ethical procedures involved in research with groups considered vulnerable. The paper will now turn to consider the impact of ethical discourse and practice on truly co-produced research.

Ethics in disability research

Even a quick reading of the literature about the recent history of the treatment of PWLD within research throws up a number of examples of horrifying abuse on a large scale, revealing a tendency to ignore the basic wellbeing and agency of those with learning disabilities; not least in Nazi Germany. For historical mistreatment of people with learning disabilities, see Bashford and Levine (2012) and Thomson (2010); for more contemporary accounts of abuse, see Oakes (2012) and Flynn and Citerella (2013). It is not surprising that the unethical practices of many nations have laid the foundations for a sheltering discourse, socially, ethically and within policy, placed around those who could be considered to lack the capacity to take part in research which concerns them. In particular, the establishment of legislative reform in the shape of The Declaration of Helsinki (1964), arose as a result of the human rights violations carried out in Nazi Germany, and elsewhere, in the name of scientific research. Outlining best practice within medical research, the Declaration answered a call for a definitive outline of acceptable international standards in all areas of medicine (Ashcroft 2011,141). The declaration is not without criticism, however, and has undergone many

reforms and clarifications (in 1975, 1983, 1989 1996, 2000, 2002,2004,2008 and 2013), but it remains a central international guidance document in the formation of laws which govern ethical medical research, ensuring that, as far as possible, eugenic abuses such as those witnessed previously could never happen again.

While it is obvious that research should never again be allowed to take precedence over the mental and physical wellbeing of participants, learning disabled or otherwise, it is problematic to suggest that the alternative is never to include PWLD within research, the dangers of 'protectionism' mentioned earlier. Wolpert [iv] (1980) suggests that, like others without disabilities, learning-disabled participants within research should be afforded the dignity of risk in taking part in research, allowing a degree of agency in the decision-making process, albeit perhaps with help from the non-learning disabled support networks around them. Atrocities such as those in Nazi Germany makes it easy to see why research with those with disabilities are so rigorously mediated by ethics committees and researchers alike, and lends weight to the importance of considering how academics approach research on and with PWLD.

**Designing co-productive research with PWLD**

The PhD from which this paper originates, had initially been devised with a focus on the move out of the institution for PWLD. As such, decisions regarding the direction of the research had been decided at an academic level; an acknowledged irony in a paper which speaks to co-produced research. Within the parameters of the study boundaries, it was therefore crucial - at least in the opinion of the researcher – to begin to include PWLD at the earliest possible stage of the research process[v]. This push for learning disabled involvement and a desire for inclusive research led to a suite of methods which made best attempt to be Inclusive and,

ultimately a tumultuous route through the ethical clearance process. The trials and tribulations of attempting such co-produced research is the subject of the following discussion.

Complexities of co-production (and back to protectionism)

Leitch (2008) argues, that the use of creative methodologies can enhance the spoken word, adding difficult to attain texture to what can be known about the lives of people with learning disabilities, these methods are not so easily embraced by those bodies through which ethical clearance must be gained. It is the creation of, and navigation through, these co-productive complexities to which the paper will now turn.

As with any research project, it is important not only to consider how the research should be approached, but also the ethical considerations which must accompany it, something particularly relevant when conducting research with PWLD. Reflecting on the historical treatment of those with LD in research, it is important to recognise the "need to protect vulnerable participant groups", while at the same time ensuring that the demands placed on the researcher "are not so restrictive as to preclude valuable research" (Iacono and Murray 2003, 49). Furthermore, it is important to be aware that being more involved in research with/about PWLD may not make them less vulnerable to the impacts of research. Some common sense is required, however, and we must also question how ethical it would be simply to exclude PWLD from research which could "provide insight into their experiences and help to shape" and change their future (Nind 2008, 6).

Jenkins (2008) argues that these transitory discourses around the understanding of vulnerability spill over into how PWLD are thought of, treated and protected by society. In

'protecting' this vulnerable group from the harsh realities of life, Davies (in Jenkins 2008, 123-124) argues that PWLD have also been stripped of their right to an "autonomous reflexive individual self" which manifests in who is considered competent to participate in research. Assuming that all PWLD are incompetent is no more fruitful than assuming that all people are competent, and it is important that the label 'learning disabled' does not preclude PWLD from taking part in research before alternative means of understanding have been explored. Expanding on this point, Angrosino (in Jenkins, 2008,5) would argue that PWLD are not incompetent because of what they do not know, since that is an inherent part of all individuals, but rather that their social interactions involve communication of a different kind, in which researchers are sometimes incapable or unwilling to partake. The term 'learning disability' arguably tells us no more, or little, about the person we are to interview than knowing their gender. Perhaps, the label should merely be used as a sign to researchers that they must look to change the modes through which they discuss, create, investigate and share knowledge during the research process, as briefly illustrated through my own partial efforts in this respect as narrated above.

Given earlier discussions regarding the treatment of PWLD within research, and the protectionist ethos that has resulted, it is understandable that projects such as this are subject to rigorous ethical approval. My own PhD study required a two-pronged process of ethical approval which was passed through both NHS Ethics (for Greater Glasgow and Clyde) and Medical, Veterinary and Life Sciences (MVLS) College (for the University of Glasgow) ethics procedure. As the data set from which I would be sampling for the mapping, questionnaire, and subsequently, interview phase of the research was held by a team within NHS, the research required clearance through the NHS Multi-centre Research Ethics Committee

(MREC).This involved working through an online Integrated Research Approval System (IRAS) form, which broke the research into various categories to allow a detailed and comprehensive review to be undertaken. Alongside the online form, the process also required a protocol, cover letter and drafts of all invitations, information sheets, questionnaires and interview transcripts which would be reviewed by the MREC ethics panel alongside the online form. The process of completing these forms to a high standard proved to be extremely time consuming and ate into most of the second year of the PhD. I found walking the line between my expectations for the research and the reality can be a frustrating experience, which relies heavily on the understanding of the ethics board in charge in order for work to be validated and, ultimately, passed as 'safe' when working with PWLD; a problematic acknowledged by Walmsley and Johnson (2003). Despite the eleven years which have passed since their article was written, my experience of navigating these tensions has been somewhat similar when attempting to undertake social science/humanities research to be approved within what is a clinical-based setting.

Goodley and Moore (2008, 887) claim that the distinctions within academia between theory and practice continue to push the academic world and the world of the "real, lived experience" further apart. I witnessed this gulf personally when I was asked to attend an NHS Ethics panel. There was unease about my inability to describe exactly which methods I would use with which individuals. This was not an attempt to be obtuse; instead, I wanted them to understand the suite of methods from which I could pick, should they be suitable for the individual in question. Although consent was eventually given, this was not without having to cede some of my ideals. I had wanted to craft a questionnaire which could be co-edited with a group of learning disabled individuals to add to the co-produced nature of the research and

to ensure that it was, as far as possible, accessible for those who would be using it, but the existing ethical protocol made prior contact impossible. I found this level of conformity difficult to navigate without feeling like I was being asked to give away little bits of my ethos for the research. It simply had to fit inside 'the box'. It had never occurred to me that the methods of inquiry which I planned to utilise were so very different so as to cause concern. To my mind I was, to rephrase Wolpert, allowing participants the 'dignity of difference' as opposed to insisting upon consistent research methods based on "conventional principles" (Aldridge, 2007, 5).

Choosing to be 'more than verbal'

While it is important to stress that 'regular', written forms of research may be perfectly suitable for some participants, it has also been integral to my work to tailor-make methods, which, where possible, transgress impairment by acknowledging its existence and embracing opportunities for alternative methodological approaches. Aldridge (2007) notes that open-ended interviews with PWLD have yielded little success and, like others, has turned to visual methodologies. Used either alone or in conjunction with more familiar 'bread and butter' methods, visual materials (pictures, drawings, symbols) can be utilised within research as both a communication tool – in the specifics of my inquiries – to aid speech and also as a tool for viewing 'home' through the eyes of respondents. The visual is not without contestation; indeed, Rose (1996) challenges the role of imagery as an objective social 'truth', instead suggesting that images can produce, reproduce and resist unequal social relations. Entangled in the creation of images is a "personal politics of enacting identity", which highlights visual media as practice and not just representation, therefore binding together points of possible correlation between the use of the visual and the portrayal of thoughts and feelings

concerning the home-space (Panelli 2004,152; Crang 1997). Rose (1996) argues that seeing and being seen are fundamental constituents of social power classification, although such a stark binary is one which this research aims to blur. Unbalancing those power relations which threaten to perpetuate PWLD as outsiders to the research can here be at least partially realised by allowing choice over what is viewed and by whom. Within my own research, I have found that 'more than verbal' methods have opened up channels of alternative conversation which can be difficult to navigate otherwise.

On entering the home of one of the first participants within this project, I was presented with a pastel drawing of the building in which he lived. This drawing included an abstract image of his building block with the hills behind, drawn in autumnal colours – his favourite time of the year he told me. Without my asking,



**Figure 3. Pastel drawing of 'home' by anonymised participant (Murray 2018, forthcoming doctoral Thesis)**

he had provided me with an artistic impression of how he viewed his home, of what mattered to him, and in this way gave me renewed vigour in my assertion that more creative methodologies can encourage participants without infantilising them. Certainly these

methods were not universally appreciated by all participants. As with those without learning disabilities, some simply did not need to be, nor see the point in, drawing pictures or taking photographs. Recognising and giving space for these decisions to be made sheds further light on the subjectivity of the learning disabled experience, giving more importance to the creation of methods which allow the voice of the participant clearly to be heard in a co-productive manner.

Exploring co-productive methodologies

I have begun to explore these ideas in more depth through case-study work with a number of learning disabled members of Inform Theatre group in Dundee (www.dundeerep.co.uk)Contact was first made with this group at *Rethinking Learning Disabilities: Contexts, voices, policies,* an ESRC funded seminar series run by Ed Hall, Chris Philo and Murray Simpson (http://www.rethinkinglearningdisability.net), where I was asked to facilitate conversations around various topics, introduced by short theatre sketches designed and performed by Inform themselves. These sketches prompted further discussion and, in particular, the success of the table cloth exercises (shown in Figure. 1. below) fuelled my interest in 'more than verbal' methods with PWLD.

Using table cloths as a blank canvas on which to express ourselves, the group (comprised of myself as an academic facilitator, several people with learning disabilities, members of Inform, parents and carers) began with topics such as 'inclusions and exclusion', topics which can be difficult to discuss. Working together, we spoke about our thoughts and feelings surrounding the terms, peppering the table cloth first

**Figure1. showing an example of the table cloth exercise from *Rethinking Learning Disabilities: Contexts, voices, policies* (http://www.rethinkinglearningdisability.net)**

of all with words. These words grew and became connected as one thought sparked another, until spider diagrams began to emerge with arms reaching between the stories of different group members as we identified similarities. As confidence grew, words turned to images, depicting scenarios regularly experienced by the group, with each member in charge of their own pen and in turn their own forms of expression. This relaxed and open form of story sharing resulted not only in a fantastic resource for research, but also a visual presentation of the thoughts, feelings and stories which depicted each person's involvement in the creation of an answer to the difficult questions posed.

Taking this approach forward in my case study work for my PhD, my participants – recruited via inform – and I started with blank pages and, together, we began to build a picture of their locational histories, using various methods combining the spoken word with visual or interactive activities. Borrowing both from Worth's (2011) time-line work (with visually impaired subjects) and Bunning and Steel's (2007) use of Talking Mats [vi], I worked with participants to create a locational time line, like the example below (Figure 2.), which begins to document moves in and out of different home spaces. Practically, this allows participants to share information about which they are experts [vii], leading gently into the unfamiliar

territory of research and creating a task where they are comfortable using their own voice. As we discussed each dwelling, be that home, hospital or respite[viii], we began to explore the feelings associated with these places by attaching either a sad, happy or indifferent face to each. Discussions around which face to use can bring forth stories in a way which is more organic than the formulaic, interview technique of question and answer. Participants described instances when they experienced happiness or sadness within the same living space and, in this way, balanced their feelings and made a decision to use either one or both of the faces, completely free of interference from myself as the researcher.
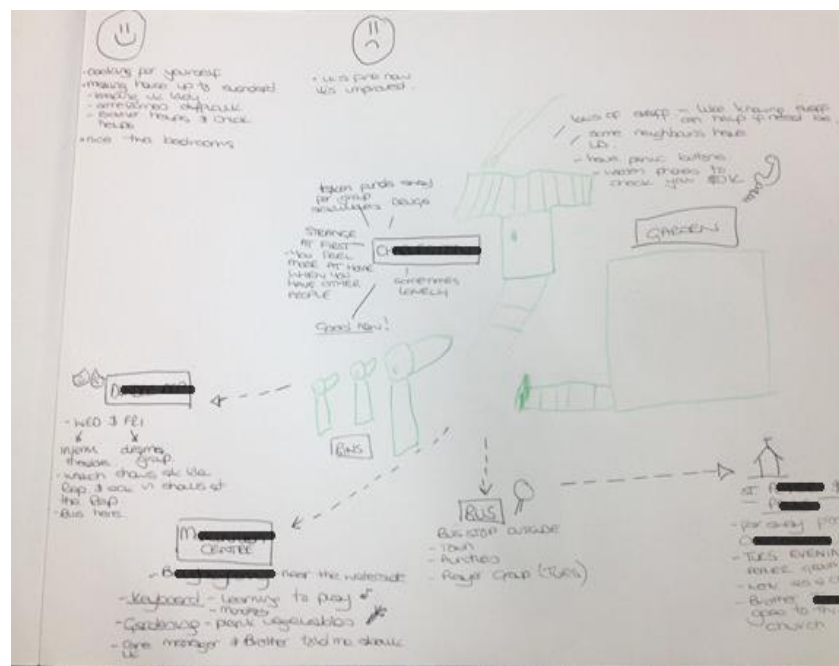


**Figure 2. Lawrence's case study map of home. (Murray 2018, forthcoming doctoral Thesis)**
Although linear, this exercise encourages participants to think about time in a straightforward way and works well as a memory aid when stories deviate, as Gaunlett (2007) suggests, turning the 'unsayable' into a familiar life-story of which participants are the author. Moreover, I have found that participants can take ownership of this method. At times I have merely had to transcribe while they lead themselves along the path created by the timeline, stopping only to ensure that I am following.

Drawing has become another way in which my participants and I can explore their home spaces at a distance, making connections to place through narrative retellings of domestic spaces (Hall 2004; Milligan 2005). Using Walmsley's (1995) network maps as inspiration for understanding and expressing the social and physical connections between people and places, my participants and I produced maps such as the one shown in Figure 2. In the drawing of the house, people tell me a little of how they view their world and point out perhaps mundane, things which make them feel 'at home', such as the bench at the front door where they spend warm days or the placement of the bins which it is their job to put out on a Tuesday.  Moreover, this focuses the home as a starting point from which the surrounding neighbourhood can be explored. It becomes a fixed space from which we can navigate, in our discussions and drawings to the other places of importance which impact on their lives. This technique also draws forth spatial observations, whereby the park is actually to the right of the house but further away than the Spar, alongside more deeply embedded social dimensions of living and interacting with neighbourhoods. By 'mapping' streets, routes and areas through which participants will not move, or feel that they cannot move, much can also be learned about social interactions within community spaces which speak to ideas of belonging and not belonging (Murray 2018, forthcoming doctoral thesis). This method encompasses the interactive nature of their lives, building connections which can be difficult to navigate verbally.

**Conclusion**

Although I paint a bleak picture, I continued forward with many of the methods which I intended to use, gathering rich and carefully considered reflections on the lives of PWLD, given to me through their own self-expression.  Unethical historical research atrocities cannot

and should not be ignored, but consideration of the abilities of those with learning disabilities must continue to be forward-facing and progressive. While maintaining protection for potentially vulnerable adults, it must also be recognised that not everybody labelled as learning disabled has the same communication wants and needs, and therefore the methods that we, as researchers, use to explore their lives must be fluid. It is important that learning disabled inclusion in research is not closed down simply because their format of expression appears non-standard.

Methodologically, I have quite deliberately worked with my core interviewee respondents in an in-depth way – their names and their words, echoing throughout the final thesis. To an extent the approach taken here echoes that of humanistic geographer Rowles (1978), really getting close to the intimate grain of lives that are, on the outside at least, seemingly quite restrained and unexciting. To be normal has been critiqued by Hansen and Philo (2007) who speak simply of 'us' all 'doing things differently'. By listening attentively and creating research alongside those for whom difference is assumed, the binaries between 'us' and 'them' continue to be destabilised. By working in a co-productive manner geographers, and others, can continue to afford so called 'vulnerable groups' the "dignity of risk" as a key part of the research process (Wolpert, 1980).

**Reference List**

**Aldridge, J 2007** Picture this: the use of participatory photographic research methods with people with learning disabilities. *Disability and Society* 22. 1-17

**Allen, Garland, E. 2008** The ideology of Elimination: American and German Eugenics, 1900-1945 in Nicosia, Francis R and Huener, Jonathan (2008) Medicine and medical Ethics in Nazi Germany: Origins, Practices, legacies. Berghahn Books, Oxford.

**Ashcroft, Richard, E. 2011** The Declaration of Helsinki *eds.* Ezekiel J. Emanuel and Christine C. Grady (2011) The Oxford Textbook of Clinical Research Ethics. *Oxford University Press, USA.*

**Atkinson, D., 1997**. *An auto/biographical approach to learning disability research*. Ashgate Publishing.

**Bunning, K. & Steel, G. 2006** Self-concept in young adults with a learning disability from the Jewish community, British Journal of Learning Disabilities, 35 43-49.

**Clements, J.,Cummins, R. and Rapley, M. 1999** On, to, for, with- vulnerable people and the practices of the research community. *Behavioural and Cognitive Psychotherapy.* 27 103-115

**Chappell, A.L. 2000** Emergence of participatory methodology in learning difficulty research: understanding the context. *British Journal of Learning Disabilities* 28 38-43

**Crang, M 1997** Picturing Practice: research through the tourist gaze. *Progress in Human Geography.* Vol.21(3), p.p.359-373.

**Flynn, M. and Citarella, V., 2013**. Winterbourne View Hospital: a glimpse of the legacy. *The Journal of Adult Protection 15* 173-181

**Gaunlett, D 2007** Creative explorations: new approaches to identities and audiences. *Routledge, London.*

**Gilbert, Tony 2000** Involving people with learning disabilities in research: issues and possibilities. *Health and Social Care in the Community* 12 298-308

 **Goodley, D. 2001** Learning Difficulties', the Social Model of Disability and Impairment: Challenging epistemologies. *Disability and Society* 16 207-231

**Hall E 2004** Social geographies of learning disabilities: narratives of exclusion and inclusion. *Area* 36 298-306

**Hansen, N. and Philo, C. 2007** The normality of doing things differently: bodies, spaces and disability geography. Tijdschrift voor economische en sociale geografie, 98:4, pp.493-506.

**Harris, John 2003** Time to make up your mind: why choosing is difficult. *British Journal of Learning Disabilities,* 31 3-8.

**Iacono, T. and Murray, V., 2003** Issues of informed consent in conducting medical research involving people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities 16.*41-51.

**Jenkins, R. 1998** Questions of Competence: culture, classification and intellectual disability. Cambridge University Press, UK

**Jurkowski, J.M. 2***008* Photovoice as Participatory Action Research Tool for Engaging People With Intellectual Disabilities in Research and Program Development. *Intellectual and Developmental Disabilities*. 46  1-11

**Kiernan, C., 1999**. Participation in research by people with learning disability: origins and issues. *British journal of learning disabilities  27* .43-47.

**Kitchin, R.M. and Hubbard, P.J., 1999** Research, action and 'critical'geographies. Area, 31(3), pp.195-198..

**Laughlin, H.H. 1922** Eugenical Sterilization in the United States. *Psychopathic laboratory of the municipal court of Chicago*

**McClimens, A 2007** This is my truth, tell me yours: exploring the internal tensions within collaborative learning disability research. *British Journal of Learning Disability* 36 271-276

**McDowell, L., 1992** Doing gender: feminism, feminists and research methods in human geography. Transactions of the institute of British Geographers, pp.399-416**.**

**McPherson, H., Hart, A. and Heaver, B. 2014** Impacts between academic researchers and community partners: Some critical reflections of impact agendas in a "visual arts for resilience" research project. *ACME* 13 27-32

**Milligan C 2005** Placing narrative correspondence in the geographers toolbox: insights from care research in New Zealand. *New Zealand Geographer* 61 213-224

**Nind, M 2008** Conducting qualitative research with people with learning, communication and other disabilities: methodological challenges. *National centre for research methods.*

**Oakes, P., 2012** Crash: what went wrong at winterbourne view? *Journal of Intellectual Disabilities, 16* 155-162.

**Panelli, R 2004** Social Geographies. Sage, London.

**Philo, C and Metzel, D (2005)** Introduction to the theme section on geographies of intellectual disability: 'Outside the participatory mainstream'? Health and Place. Vol.11, p.p. 77-85.Rose, G. 2000 Visual methodologies. Sage, London.

**Routledge, in Kitchin and Thrift 2009,** International encyclopedia of human geography. Elsevier.

**Rowles, G.D. (1978)** Prisoners of space?: Exploring the geographical experience of older people. Westview Press.

**Shakespeare, T 2006**. The social model of disability. *The disability studies reader* 2  197-204.

**Stalker, K 1998** Some ethical and methodological issues in research with people with learning difficulties. *Disability and Society*. 13 5-19.

**Thomson, Mathew 2010** Disability, Psychiatry and Eugenics in Bashford and Levine (2012) Oxford Handbook of the History of Eugenics,. Oxford university press.

**Walmsley, J., 2004** Inclusive learning disability research: The (nondisabled) researcher's role. *British Journal of Learning Disabilities*, *32* 65-71.

**Walmsley, J. and Johnson, K., 2003**. *Inclusive research with people with learning disabilities: Past, present and futures*. Jessica Kingsley Publishers.

**Wolpert, J., 1980**. The dignity of risk. *Transactions of the Institute of British Geographers*b .391-401.

**Worth, N. 2011** Evaluating life maps as a versatile method for lifecourse geographies. *Area* 43 405-412

**Yardley, A. 2008** Piecing together: a methodological bricolage. *Forum:Qualitative Social*

*Reseach* 9

[i] Of course for some people with limited resources and/or needs to be proximate to places of paid work, education, caring, etc., these decisions may still be highly circumscribed.

[ii] I have chosen to echo the thoughts of Ward and Flynn (1994) by selecting the term 'learning Disabilities' in which people with learning disabilities themselves within the UK have had some stake as part of the definitional process, recognising 'learning disabled' as the chosen language of charities and advocacy groups. Within this terminology I include those with mild, moderate and severe learning disabilities including Dyslexia, Downs Syndrome and Edwards Syndrome.

[iii] Of course, in contemporary human geography, participatory research is not normally seen in this light, nor so divorced from emancipatory geographies (Rose, 1996; McDowell, 1992; Kitchin and Hubbard, 1999) – albeit Routledge (2009) does go some way to suggesting that research can be participatory, involving active participation with research subjects, but abandoning and critical or emancipatory edge.

[iv] This remarkably early contribution by a geographer, long before anything like a field of geographical enquiry on learning or intellectual disability (Hall and Kearns, 2001; Philo and Metzel, 2005) was apparent, particularly considered the danger of 'protectionism' in research with people with learning disabilities.

[v] Most respondent names have been pseudonymised to protect participant identities in accordance with ethical clearance. One exception is Lawrence who requested to retain his own name and separate permissions were sought for this.

[vi] Talking Mats (http://www.talkingmats.com) are a set of pictorial symbols which can be used across a broad spectrum of communicational needs to allow effective communication about subjects of importance.

[vii] Taking seriously the broader idea of research subjects being 'experts in their own lives'.

[viii] 'Home' speaks to those dwellings where PWLD live or have lived, which could be on their own, with parents, with carers, with other with learning disabilities or any combination thereof which might best describe their living accommodation. For many PWLD, hospitals have also been home, either through long term institutionalisation because of their learning disabilities or as a result of co-morbidities. Respite, represents those places which many PWLD attend for short periods of full time care away from the family unit, allowing recuperation and a break from the normal stresses associated with everyday life.