**ABSTRACT**

**Disabled citizens as researchers – Challenges and benefits of collaboration for effective action and change.**

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This article reports on the evaluation of an initial pilot for a collaborative research project undertaken in an English county between a service user-led Coalition of Disabled People, the local authority and local university. The project sought to map the assets and resources for/of disabled people in their local community as well as needs and gaps, to inform the Coalition’s strategic planning and raise awareness of disability issues across the county.

The article discusses an inclusive, co-productive approach using participatory action research. It focuses on experiences from the pilot stage of the project and considers how the authors worked together with the required knowledge exchange and power-sharing to recruit and train researchers with expertise from their personal experience of disability. Recruitment ensured they had relevant qualities and skills that could be developed, to increase their confidence, knowledge and skills set as researchers. They then undertook photo-elicited, semi-structured interviews with other disabled people, analysed findings and created photographic exhibitions for dissemination and awareness raising.

Demonstrating a commitment to emancipatory research and collective action for change, the discussion considers the promotion of shared values within the research team, and explores the benefits and challenges encountered during the process and how the particular stages were managed to achieve the beneficial outcomes of the pilot. The article seeks to add to the literature of participatory/emancipatory action research for social work.

KEYWORDS: [Participatory action research](https://www.tandfonline.com/keyword/Participatory%2BAction%2BResearch), [photo-elicitation](https://www.tandfonline.com/keyword/Photo-elicitation), [social change agenda](https://www.tandfonline.com/keyword/Social%2BChange%2BAgenda), [citizen activism](https://www.tandfonline.com/keyword/Citizen%2BActivism)

**Introduction**

This article presents a discussion of the collaboration between members the Coalition of Disabled People (SCODP), formed to improve the lives of disabled people in the locality, and two researchers from a local university and local authority, who came together to devise a project to inform the Coalition’s strategy, which developed into a participatory action research project, based on emancipatory principles. The ensuing discussion provides an evaluation of the pilot phase of the project, reflecting on the benefits and challenges that arose using this research approach with a group of disabled people seeking improvement in their quality of life.

**The research context**

When a local Coalition of Disabled People (SCODP) was set up in 2013, it was the first coalition of its kind in the local area that brought together a number of organisations for people with a broad range of disabilities within an English County. Coalitions of Disabled People have developed in the UK at local level as a way for disabled people to share knowledge, experience and information, attend workshops and events, and campaign on local and national issues. On this last aim, Coalitions still have much scope for campaigning;

While progress has been made in some areas, the overall picture emerging from the data is that disabled people are facing more barriers and falling further behind. It is a badge of shame on our society that millions of disabled people in Britain are still not being treated as equal citizens and continue to be denied the everyday rights non-disabled people take for granted … .

(Equality and Human Rights Commission, [2017](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Equality and Human Rights Commission. (2017). *Being disabled in Britain. A journey less equal*. London: Equality and Human Rights Commission. Retrieved from:[https://www.equalityhumanrights.com/sites/default/files/being-disabled-in-britain.pdf](https://www.equalityhumanrights.com/sites/default/files/being-disabled-in-britain.pdf%22%20%5Ct%20%22_blank). [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2017&author=Equality+and+Human+Rights+Commission&title=Being+disabled+in+Britain.+A+journey+less+equal), p. 7).

In its early days, it was apparent that SCODP required a knowledge base about the current level and extent of services and resources available within the county for disabled people, their usefulness and effectiveness. To this end, in collaboration with the University of Suffolk and County Council (SCC), SCODP set about establishing a research project to ascertain the numbers of people with a disability in the county, the services available to them, existing facilities and resources, and any perceived gaps and omissions resulting in unmet need, from the perspective of local disabled people. This could then be used to seek improvements for disabled people in the local community, led by the Coalition. To determine a strategy for local activism, it was necessary to ensure that the views and perceptions of disabled people in the area were given a collective voice to articulate their needs and wishes, and to improve their community participation.

In order to develop a clear understanding of the demand for current and future services across the county, the Project Co-ordinating Team developed a three-phase scoping exercise devised to;

1. determine the numbers of disabled people living in and using Adult Services in the county (from existing SCC statistics)
2. provide an overview of existing resources through a telephone audit, using Coalition members to provide information about services they had used/were using, and
3. undertake an in-depth exploration using a qualitative approach (semi-structured interviews) to achieve a more detailed understanding of the experiences of disabled people within the county to ascertain what works and what does not work for them in their daily lives.

The first two phases were completed by SCC and SCODP in 2015. This article focuses on the pilot for the third phase of the project and its impact locally during 2016/17.

**Co-producing the research**

Co-production has become a significant tool for ‘service user’ participation in policy implementation, service delivery and service improvement in many European countries, as commissioners and providers in social care seek to maintain quality of service against a landscape of sustained cuts to services (Pestoff, Brandsen, & Verschuere, [2013](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Pestoff, V., Brandsen, T., & Verschuere, B. (2013). *New public governance, the third sector and co-production*. London: Routledge.[[Crossref]](https://www.tandfonline.com/servlet/linkout?suffix=CIT0037&dbid=16&doi=10.1080%2F13691457.2018.1564736&key=10.4324%2F9780203152294), , [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2013&author=V.+Pestoff&author=T.+Brandsen&author=B.+Verschuere&title=New+public+governance%2C+the+third+sector+and+co-production)). Whilst this may suggest potential exploitation of people who use services (Cahn, [2004](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Cahn, E. S. (2004). *No more throw away people. The co-production imperative*. Washington, DC: Essential Books. [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2004&author=E.+S.+Cahn&title=No+more+throw+away+people.+The+co-production+imperative), p. 25), there is also the potential for gain for all involved, as will be demonstrated below. From the start, the values of co-production were embodied, aiming to carry out the project with reference to the top rung (citizen control) of Arnstein’s Ladder of Participation (Arnstein, [1971](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Arnstein, S. (1971). A ladder of citizen participation. *Journal of the Royal Planning Institute*, *35*(4), 216–224. [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=1971&pages=216-224&issue=4&author=S.+Arnstein&title=A+ladder+of+citizen+participation)). Within social research, the development of a community-based participatory research paradigm offers a more inclusive and democratic approach to address research priorities at a local level. Relating this to co-production, it is ‘the practice of engaging those whose lives are impacted by the research directly into the research process’ (Boser, [2006](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Boser, S. (2006). Ethics and power in community-campus partnerships for research. *Action Research*, *4*(1), 9–21. doi: 10.1177/1476750306060538[[Crossref]](https://www.tandfonline.com/servlet/linkout?suffix=CIT0012&dbid=16&doi=10.1080%2F13691457.2018.1564736&key=10.1177%2F1476750306060538), , [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2006&pages=9-21&issue=1&author=S.+Boser&title=Ethics+and+power+in+community-campus+partnerships+for+research), p. 11).

**A shared value base**

Participatory research has a well-developed history (e.g. Beresford, [2000](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Beresford, P. (2000). Service users’ knowledge and social work theory: Conflict or collaboration? *British Journal of Social Work*, *30*(4), 489–503. doi: 10.1093/bjsw/30.4.489[[Crossref]](https://www.tandfonline.com/servlet/linkout?suffix=CIT0009&dbid=16&doi=10.1080%2F13691457.2018.1564736&key=10.1093%2Fbjsw%2F30.4.489), [[Web of Science ®]](https://www.tandfonline.com/servlet/linkout?suffix=CIT0009&dbid=128&doi=10.1080%2F13691457.2018.1564736&key=000088912600006), , [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2000&pages=489-503&issue=4&author=P.+Beresford&title=Service+users%E2%80%99+knowledge+and+social+work+theory%3A+Conflict+or+collaboration%3F); Nolan, Hanson, Grant, & Keady, [2007](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Nolan, M., Hanson, E., Grant, G., & Keady, J. (2007). *User participation in health and social care research*. Maidenhead: Open University Press. [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2007&author=M.+Nolan&author=E.+Hanson&author=G.+Grant&author=J.+Keady&title=User+participation+in+health+and+social+care+research); Reason, [1994](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Reason, P. (1994). *Participation in human inquiry*. London: Sage. [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=1994&author=P.+Reason&title=Participation+in+human+inquiry); Reason & Bradbury, [2008](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Reason, P., & Bradbury, H.(Eds.). (2008). *The Sage Book of action research: Participative inquiry and practice* (2nd ed.). London: Sage.[[Crossref]](https://www.tandfonline.com/servlet/linkout?suffix=CIT0041&dbid=16&doi=10.1080%2F13691457.2018.1564736&key=10.4135%2F9781848607934), , [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2008&author=P.+Reason&author=H.+Bradbury&title=The+Sage+Book+of+action+research%3A+Participative+inquiry+and+practice)). A participatory and co-productive approach, which values marginalised groups like disabled people as citizens and active asset holders, rather than passive consumers of services, was essential to this project, as the Coalition sought to promote the voices of local disabled people to improve their visibility and power to effect change in their community. Equally, the assets of professionals were important, combined with those of disabled people within a reciprocal relationship. Dzur positions professionals ‘as facilitators in a more active and engaged democracy’ (Dzur, [2008](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Dzur, A. W. (2008). *Democratic professionalism. Citizen participation and the reconstruction of professional ethics, identity and practice*. University Park, PA: The Pennsylvania State University Press. [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2008&author=A.+W.+Dzur&title=Democratic+professionalism.+Citizen+participation+and+the+reconstruction+of+professional+ethics%2C+identity+and+practice), p. 105), based within citizen participation and citizen action, and Cahn, in his work on co-production, stresses the significance of reciprocity and mutuality, stating that ‘by creating parity for individuals and communities in their relationships with professional helpers, it gave promise of effecting systemic change’ (Cahn, [2004](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Cahn, E. S. (2004). *No more throw away people. The co-production imperative*. Washington, DC: Essential Books. [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2004&author=E.+S.+Cahn&title=No+more+throw+away+people.+The+co-production+imperative), p. 23).

Based on these principles of parity of contribution, mutuality and reciprocity, a project co-ordination team comprising representatives from SCODP, the SCC and the university met on a regular basis to plan the project and source funding, and quickly developed a shared value base, establishing trust and common ground based on an appreciation of the social model of disability (Barnes, [1998](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Barnes, C. (1998). The social model of disability: A sociological phenomenon ignored by sociologists. In T.Shakespeare (Ed.), *The disability reader: Social science perspectives* (pp. 65–78). London: Continuum. [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=1998&pages=65-78&author=C.+Barnes&title=The+disability+reader%3A+Social+science+perspectives); Oliver, [2009](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Oliver, M. (2009). *Understanding disability: From theory to practice* (2nd ed.). London: Palgrave Macmillan.[[Crossref]](https://www.tandfonline.com/servlet/linkout?suffix=CIT0034&dbid=16&doi=10.1080%2F13691457.2018.1564736&key=10.1007%2F978-1-137-05492-0), , [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2009&author=M.+Oliver&title=Understanding+disability%3A+From+theory+to+practice)) and the absolute requirement that the research should be carried out by disabled people themselves, researching the views and experiences of other disabled people from a position of shared understanding with a goal of social action and change.

Importantly, as an organisation led by disabled people for disabled people SCODP sought to ensure that the slogan ‘nothing about us without us’ (Charlton, [1998](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Charlton, J. (1998). *Nothing about us without us*. Berkeley: University of California Press.[[Crossref]](https://www.tandfonline.com/servlet/linkout?suffix=CIT0015&dbid=16&doi=10.1080%2F13691457.2018.1564736&key=10.1525%2Fcalifornia%2F9780520207950.003.0001), , [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=1998&author=J.+Charlton&title=Nothing+about+us+without+us)), which stresses disabled people’s valid expertise from experience, was incorporated into its collective campaigning and lobbying for effective and appropriate resources and services for disabled people. Therefore the research had to reflect the same approach and to incorporate an activist stance to the research findings to promote change. In this sense, co-production was developed in two phases – in that of the planning and execution of the research project and then in the application of its findings to pursue change and improvement in the lives of disabled people. This shared value base was extremely important for sustaining the project, as without it there could have been the danger of researchers and participants losing interest in the project, or power dynamics and relationships moving away from a truly joint enterprise.

**Power and meaning**

SCODP as an organisation locates itself within a socio-political interpretation of disability, viewing disability as social oppression (Barnes, [2003](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Barnes, C. (2003). What a difference a decade makes. Reflections on doing emancipatory disability research. *Disability and Society*, *18*(1), 13–17. doi: 10.1080/713662197[[Taylor & Francis Online]](https://www.tandfonline.com/doi/10.1080/713662197), [[Web of Science ®]](https://www.tandfonline.com/servlet/linkout?suffix=CIT0007&dbid=128&doi=10.1080%2F13691457.2018.1564736&key=000180524400001), , [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2003&pages=13-17&issue=1&author=C.+Barnes&title=What+a+difference+a+decade+makes.+Reflections+on+doing+emancipatory+disability+research), p. 5), so the approach to this research project had to sit within this contested and politicised area of study, which challenges the individualising and objectifying medical models of disability. In researching indigenous communities, Smith ([2012](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Smith, L. T. (2012). *De-colonising methodologies: Research and indigenous people*. London: Zed Books Ltd. [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2012&author=L.+T.+Smith&title=De-colonising+methodologies%3A+Research+and+indigenous+people)) showed how research with indigenous populations can be a process of colonisation and of resistance to this, and that ‘decolonising methodologies’ to promote emancipatory research challenge fundamental ontological and epistemological positions about the nature of knowledge and how it is produced, depending on where the researcher is positioned within the social hierarchy. Similarly, for disabled people, traditional research has enabled the non-disabled academic researcher to take the power to construct meaning from disabled participants’ experiences and knowledge and build this knowledge through their own identity, lens and representations (within dominant ways of knowing) (Oliver, [1992](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Oliver, M. (1992). Changing the social relations of research production. *Disability, Handicap and Society*, *7*(2), 101–114. doi: 10.1080/02674649266780141[[Taylor & Francis Online]](https://www.tandfonline.com/doi/10.1080/02674649266780141), , [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=1992&pages=101-114&issue=2&author=M.+Oliver&title=Changing+the+social+relations+of+research+production)). This can be viewed as a way of colonising their experiences. Humphries ([1994](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Humphries, B. (1994). Empowerment and social research: Elements for an analytical framework. In B.Humphries & C. Truman (Eds.), *Rethinking social research. Anti-discriminatory approaches in research methodology* (pp. 185–204). Aldershot: Ashgate. [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=1994&pages=185-204&author=B.+Humphries&title=Rethinking+social+research.+Anti-discriminatory+approaches+in+research+methodology), pp. 191–194) takes a similar view in feminist research, stating that this results in accumulation and appropriation of power. From the perspective of the disabled ‘’ researchers and the participants in this research project, the constructivist approach was already part of the world-view of members of a Coalition of disabled people looking for a voice and for transformative action.

**Methodological choices *–* key issues**

**A qualitative, participatory action approach**

A qualitative approach was chosen, with disabled researchers (trained within the project) interviewing other local disabled people to explore the depth and detail of disabled people’s social experiences and the benefits (what works) and barriers (what does not work) they encounter in their daily lives. The participatory/collaborative approach (Reason, [1994](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Reason, P. (1994). *Participation in human inquiry*. London: Sage. [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=1994&author=P.+Reason&title=Participation+in+human+inquiry)) to research was adopted in a pragmatic way to empower those marginalised and powerless. It allowed for the exploration of social constructions that maintain the status quo for the benefit of those more powerful (Alston & Bowles, [2018](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Alston, M., & Bowles, W. (2018). *Research for social workers. An introduction to methods* (4th ed.). London: Allen and Unwin. [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2018&author=M.+Alston&author=W.+Bowles&title=Research+for+social+workers.+An+introduction+to+methods)). Action research (Winter & Munn-Giddings, [2001](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Winter, R., & Munn-Giddings, C.(2001). *A handbook for action research in health and social care*. London: Routledge.[[Crossref]](https://www.tandfonline.com/servlet/linkout?suffix=CIT0050&dbid=16&doi=10.1080%2F13691457.2018.1564736&key=10.4324%2F9780203199671), , [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2001&author=R.+Winter&author=C.+Munn-Giddings&title=A+handbook+for+action+research+in+health+and+social+care), p. 8) is defined as ‘the study of a social situation carried out by those involved in that situation in order to improve both their practice and the quality of their understanding’, and sits closely with participatory/emancipatory research (Seale, [2018](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Seale, C. (2018). Philosophy, politics and values. In C. Seale(Ed.), *Researching society and culture* (4th ed., pp. 22–23). London: Sage. [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2018&pages=22-23&author=C.+Seale&title=Researching+society+and+culture), p. 22). As Boser ([2006](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Boser, S. (2006). Ethics and power in community-campus partnerships for research. *Action Research*, *4*(1), 9–21. doi: 10.1177/1476750306060538[[Crossref]](https://www.tandfonline.com/servlet/linkout?suffix=CIT0012&dbid=16&doi=10.1080%2F13691457.2018.1564736&key=10.1177%2F1476750306060538), , [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2006&pages=9-21&issue=1&author=S.+Boser&title=Ethics+and+power+in+community-campus+partnerships+for+research), p. 11) suggests;

Action research projects are often conducted with an explicit social change agenda, and work from the belief that the very process of participating in constructing knowledge about one’s own context has the potential to redress power imbalance.

In terms of power relationships and the control of the research process and agenda, Beresford’s discussion about democratisation of the research process was also particularly relevant (Beresford, [2002](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Beresford, P. (2002). User involvement in research and evaluation: Liberation or regulation? *Social Policy and Society*, *1*(2), 95–105. doi: 10.1017/S1474746402000222[[Crossref]](https://www.tandfonline.com/servlet/linkout?suffix=CIT0010&dbid=16&doi=10.1080%2F13691457.2018.1564736&key=10.1017%2FS1474746402000222), , [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2002&pages=95-105&issue=2&author=P.+Beresford&title=User+involvement+in+research+and+evaluation%3A+Liberation+or+regulation%3F)). Ownership of the research involved consideration of power within the research team and between the project co-ordination team, the researchers and the participants. To equalise the research relationship, it was important to ensure that the research was co-produced throughout by all involved, and to this end group meetings with researchers and the project team were a key feature during the data collection phase and then additionally with participants in the analysis phase. This approach addressed the issue of who owns the knowledge in order to use it to change material conditions and to hold accountability for the research outcomes and their application. For this project, the findings from the pilot were acted upon through the use of exhibitions to disseminate findings, which raised the profile of the disabled researchers and, as a major benefit, led them into consultative roles with local planners and developers, thereby increasing their visibility and power to promote change in their own lives.

**Transformative potential**

The inclusion of disabled people in the management of this research project was therefore crucial and significant in achieving the necessary control of the use of the research findings to promote change. The emancipatory disability research tradition has a transformative aim and Oliver ([1992](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Oliver, M. (1992). Changing the social relations of research production. *Disability, Handicap and Society*, *7*(2), 101–114. doi: 10.1080/02674649266780141[[Taylor & Francis Online]](https://www.tandfonline.com/doi/10.1080/02674649266780141), , [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=1992&pages=101-114&issue=2&author=M.+Oliver&title=Changing+the+social+relations+of+research+production)) makes it clear that research should not be merely about investigation for the accumulation of knowledge (about disabled people, reflecting their position within social hierarchies) but that the knowledge acquired through investigation must be used to change material conditions for disabled people. This emphasis on praxis or achieving change for the benefit of disabled people was therefore important to achieve in this project.

In summary, the research was designed to meet the key characteristics of emancipatory research as outlined by Barnes ([2003](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Barnes, C. (2003). What a difference a decade makes. Reflections on doing emancipatory disability research. *Disability and Society*, *18*(1), 13–17. doi: 10.1080/713662197[[Taylor & Francis Online]](https://www.tandfonline.com/doi/10.1080/713662197), [[Web of Science ®]](https://www.tandfonline.com/servlet/linkout?suffix=CIT0007&dbid=128&doi=10.1080%2F13691457.2018.1564736&key=000180524400001), , [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2003&pages=13-17&issue=1&author=C.+Barnes&title=What+a+difference+a+decade+makes.+Reflections+on+doing+emancipatory+disability+research)) as follows;

* there was direct accountability to the organisation(s) controlled and run by disabled people (SCODP);
* there was a commitment to the social model of disability;
* the choice of methodology and methods was qualitative;
* and there were to be meaningful practical outcomes for disabled people locally.

**Authenticity and voice**

Furthermore, it was important to ensure authenticity through capturing the expressed meanings of disabled participants, with the use of a shared understanding created with disabled researchers as ‘insider’ researchers (Corbin Dwyer & Buckle, [2009](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Corbin Dwyer, S., & Buckle, J.(2009). The space In-between: On being and insider-outsider in qualitative research. *International Journal of Qualitative Research*, *8*(1), 54–63. [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2009&pages=54-63&issue=1&author=S.+Corbin+Dwyer&author=J.+Buckle&title=The+space+In-between%3A+On+being+and+insider-outsider+in+qualitative+research)), to ensure that the voice of participants finds clear expression within the research in relation to their socio-economic situations. Strangeness and familiarity (Flick, [2014](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Flick, U. (2014). *An introduction to qualitative research* (5th ed.). London: Sage. [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2014&author=U.+Flick&title=An+introduction+to+qualitative+research), pp. 162–3) (or ‘outsider’ and ‘insider’ positioning of the researcher) have long been issues for consideration in anthropology and ethnography and there are positives and negatives for both positionings (Padgett, [2017](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Padgett, D. K. (2017). *Qualitative methods in social work research*(3rd ed.). London: Sage. [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2017&author=D.+K.+Padgett&title=Qualitative+methods+in+social+work+research), pp. 65–66). This also relates to the involvement of non-disabled researchers within the project co-ordination team (two of the three members), and the legitimacy of their position. Goodley ([2017](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Goodley, D. (2017). *Disability studies. An interdisciplinary introduction* (2nd ed.). London: Sage. [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2017&author=D.+Goodley&title=Disability+studies.+An+interdisciplinary+introduction)) reports on how disabled researchers have welcomed the contributions of non-disabled researchers, and it is our view (in accordance with Aspis, [1997](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Aspis, S. (1997) Inclusion and exclusion. Paper presented at the social history of learning disability Conference ‘inclusion and exclusion’, the open university, Walton Hall, Milton Keynes, 10 December. [[Google Scholar]](http://scholar.google.com/scholar?hl=en&q=Aspis%2C+S.+%281997%29++Inclusion+and+exclusion.+Paper+presented+at+the+social+history+of+learning+disability+Conference+%E2%80%98inclusion+and+exclusion%E2%80%99%2C+the+open+university%2C+Walton+Hall%2C+Milton+Keynes%2C+10+December.) and [1999](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Aspis, S. (1999). What they don’t tell disabled people with learning difficulties. In S.Corker & S. French (Eds.), *Disability Discourse* (pp. 173–182). Buckingham: Open University Press. [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=1999&pages=173-182&author=S.+Aspis&title=Disability+Discourse)) that non-disabled researchers can contribute to this field of research if their value base is compatible, i.e. a commitment to emancipatory research as allies of disabled people seeking change for a more just society. As Shakespeare comments, Participatory Action Research (PAR) can include non-disabled researchers as long as they have commitment, *‘*doing so from an engaged position, with the ultimate goal of helping improve the lives of disabled people (Shakespeare, [2015](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Shakespeare, T. (2015). *Disability research today. International perspectives*. London: Routledge. [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2015&author=T.+Shakespeare&title=Disability+research+today.+International+perspectives), p. 3).

The following section will provide details of the research process and will highlight significant issues encountered, which were considered as part of the evaluation.

**Research process**

The Project Co-ordinating Team put together a research governance application, which was successful. They outlined the recruitment of the researchers (ie. job description, advertising and selection process) and their training. They organised the selection of the participants and tracked funding applications, monitored spending, set up the interviews, and arranged the data analysis sessions (carried out together by the researchers and the Project Co-ordinating Team). The initial ‘pilot’ phase was undertaken within the county town during 2016, with a view to expanding the project across other areas within the county, applying the learning gained in the ‘pilot’ phase.

The research process broadly followed the three phase model developed by Cunningham ([1976](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Cunningham, B. (1976). Action research: Towards a procedural model. *Human Relations*, *29*(3), 215–238. doi: 10.1177/001872677602900302[[Crossref]](https://www.tandfonline.com/servlet/linkout?suffix=CIT0018&dbid=16&doi=10.1080%2F13691457.2018.1564736&key=10.1177%2F001872677602900302), [[Web of Science ®]](https://www.tandfonline.com/servlet/linkout?suffix=CIT0018&dbid=128&doi=10.1080%2F13691457.2018.1564736&key=A1976BN88000002), , [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=1976&pages=215-238&issue=3&author=B.+Cunningham&title=Action+research%3A+Towards+a+procedural+model)), as cited in Bortolletto ([2017](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Bortolletto, N. (2017). Participatory action research in local development: An opportunity for social work. *European Journal of Social Work*, *20*(4), 484–496. doi: 10.1080/13691457.2016.1188770[[Taylor & Francis Online]](https://www.tandfonline.com/doi/10.1080/13691457.2016.1188770), [[Web of Science ®]](https://www.tandfonline.com/servlet/linkout?suffix=CIT0011&dbid=128&doi=10.1080%2F13691457.2018.1564736&key=000406101200004), , [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2017&pages=484-496&issue=4&author=N.+Bortolletto&title=Participatory+action+research+in+local+development%3A+An+opportunity+for+social+work)), in that there was a group development process that occurred in two stages in this project – that of the creation of a group identity for the project co-ordination team which then, through the recruitment and training, expanded to include the researchers during the research phase and then the action phase.

Researchers and participants were recruited using SCODP's networks and local media. On this basis, they were self-selecting, which did raise issues around diversity, which will be considered later. Initial contact was through a named representative of SCODP, who was available to answer questions and discuss any finer points of the co-produced job descriptions. This initial contact was also an opportunity to reassure potential researchers and participants that the recruitment and training sessions would be held in accessible spaces and any barriers to attendance would be removed. The use of the university worked well in this respect because physical access and other amenities are all accessible. It also elevated the project in the eyes of the SCODP members, that this was a serious endeavour. A fun and relaxed recruitment day was held to assess the skills of the potential researchers in relationship-building and empathy. This time was also an opportunity to develop together five training sessions, during which role play was used to build the researchers’ interviewing skills and their confidence. Also, the shared understandings and expertise of the researchers were acknowledged and built on, and the interview schedule was put together collectively during these training sessions.

**Data collection**

Semi-structured interviews were used to collect data, in preference to, for example, focus groups, as this was the preference of the researchers and the Coalition to allow in depth exploration with individual participants in a more ‘protected’ setting. Interviews are one of the most commonly used methods of data collection (DiCicco-Bloom & Crabtree, [2006](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)DiCicco-Bloom, B., & Crabtree, B. F. (2006). The qualitative research interview. *Medical Education*, *40*(4), 314–321. doi: 10.1111/j.1365-2929.2006.02418.x[[Crossref]](https://www.tandfonline.com/servlet/linkout?suffix=CIT0019&dbid=16&doi=10.1080%2F13691457.2018.1564736&key=10.1111%2Fj.1365-2929.2006.02418.x), [[PubMed]](https://www.tandfonline.com/servlet/linkout?suffix=CIT0019&dbid=8&doi=10.1080%2F13691457.2018.1564736&key=16573666), [[Web of Science ®]](https://www.tandfonline.com/servlet/linkout?suffix=CIT0019&dbid=128&doi=10.1080%2F13691457.2018.1564736&key=000236385100007), , [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2006&pages=314-321&issue=4&author=B.+DiCicco-Bloom&author=B.+F.+Crabtree&title=The+qualitative+research+interview)). Semi-structured interviews allowed the researchers to jointly prepare with the project co-ordination team the open questions and topics for the interview ‘guide’ in the final stage of their training sessions. The guidelines included suggestions on how the researcher should introduce themselves to participants to help them to relax and included paying attention to body language, together with reflecting back their understanding of responses to questions for participants to clarify. Interview questions and topics for discussion were prepared together during the final training sessions in a broad and flexible way as follows;

1. Access to services in your local area?
2. What about your social life?
3. Employment and volunteering
4. Experiences/attitudes both positive and negative
5. How would you rate your overall Quality of Life? (if appropriate)

To conclude the interview researchers thanked participants and ensured they ended on a positive note.

This method also allowed the researchers the flexibility during interviews to probe and further discuss what were sometimes sensitive issues, giving a greater exploration of responses in each interview. An additional benefit of semi-structured interviewing is that it can provide reliable, comparable qualitative data. All interviews were taped (with permission from the participants) and transcribed after each interview. Care was taken to ensure that none of the researchers and participants were known to each other prior to interview.

There were five researchers and nine participants involved in the research, with four of the researchers interviewing two participants. One of the researchers was unavailable for the second interview session, therefore nine participants were interviewed. Most of the researchers had no previous experience of research but had relevant skills and abilities that could be harnessed and applied to the research context through the training offered. This provided a developmental opportunity for the researchers in terms of personal growth (Wilkins, [2000](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Wilkins, P. (2000). Collaborative approaches to research. In B.Humphries (Ed.), *Research in social care and social welfare. Issues and debates for practice*(pp. 16–30). London: Jessica Kingsley. [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2000&pages=16-30&author=P.+Wilkins&title=Research+in+social+care+and+social+welfare.+Issues+and+debates+for+practice), p. 20) – in particular a growth in confidence and self-esteem, already mentioned, which proved a major benefit for the researchers.

A photo-elicitation method (Harper, [2002](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Harper, D. (2002). Talking about pictures: A case for photo-elicitation. *Visual Studies*, *17*(1), 13–26. doi: 10.1080/14725860220137345[[Taylor & Francis Online]](https://www.tandfonline.com/doi/10.1080/14725860220137345), , [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2002&pages=13-26&issue=1&author=D.+Harper&title=Talking+about+pictures%3A+A+case+for+photo-elicitation)) was also used after discussion and exploration of this technique in the research training sessions. The disabled researchers were particularly interested in using this as a way to focus the interviews. For a more inductive research approach, researchers ask their interview subjects to take their own photos to be used later as interview stimuli. This is sometimes called a photo-elicitation interview (Clark, [1999](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Clark, C. D. (1999). The autodriven interview: A photographic viewfinder into children’s experience. *Visual Sociology*, *14*(1/2), 39–50. doi: 10.1080/14725869908583801[[Taylor & Francis Online]](https://www.tandfonline.com/doi/10.1080/14725869908583801), , [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=1999&pages=39-50&issue=1%2F2&author=C.+D.+Clark&title=The+autodriven+interview%3A+A+photographic+viewfinder+into+children%E2%80%99s+experience)). This approach to data collection can also be linked to arts-based approaches that have gained some favour within social work research. Bell ([2017](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Bell, L. (2017). *Research methods for social Workers*. London: Palgrave Macmillan.[[Crossref]](https://www.tandfonline.com/servlet/linkout?suffix=CIT0008&dbid=16&doi=10.1080%2F13691457.2018.1564736&key=10.1057%2F978-1-137-44283-3), , [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2017&author=L.+Bell&title=Research+methods+for+social+Workers), p. 143) notes that;

This ‘arts-based practice’ may often cross boundaries between research, evaluation and therapeutic practice, and as such this would be an interesting model to explore and develop further within social work research.

This technique was particularly useful in the ‘action’ phase of the project as the photos formed the basis of an exhibition that developed out of the pilot project (see below).

So, before each interview, all participants were issued with a disposable camera to capture their daily lives with the emphasis on ‘what works’ and ‘what could be better’ in their daily lives. These photographs (taken where necessary with permission) of situations and occurrences that either worked well or did not work at all for them, acted as the catalyst for the interviews. They were used to build rapport at the beginning of interviews and for deeper probing throughout the interviews. Several of the researchers reported that this method facilitated a good interview from the outset and aided confidence-building throughout, thereby helping to alleviate any anxieties felt by the researchers prior to the interviews. Harper ([2002](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Harper, D. (2002). Talking about pictures: A case for photo-elicitation. *Visual Studies*, *17*(1), 13–26. doi: 10.1080/14725860220137345[[Taylor & Francis Online]](https://www.tandfonline.com/doi/10.1080/14725860220137345), , [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2002&pages=13-26&issue=1&author=D.+Harper&title=Talking+about+pictures%3A+A+case+for+photo-elicitation)) highlights the collaborative aspect of this approach, which is of significance for this project *‘*when two or more people discuss the meaning of photographs they try to figure out something together’. (Harper, [2002](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Harper, D. (2002). Talking about pictures: A case for photo-elicitation. *Visual Studies*, *17*(1), 13–26. doi: 10.1080/14725860220137345[[Taylor & Francis Online]](https://www.tandfonline.com/doi/10.1080/14725860220137345), , [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2002&pages=13-26&issue=1&author=D.+Harper&title=Talking+about+pictures%3A+A+case+for+photo-elicitation), p. 23).

Further, Foster ([2012](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Foster, V. (2012). The pleasure principle: Employing arts-based methods in social work research. *European Journal of Social Work*, *15*(4), 532–545. doi: 10.1080/13691457.2012.702311[[Taylor & Francis Online]](https://www.tandfonline.com/doi/10.1080/13691457.2012.702311), [[Web of Science ®]](https://www.tandfonline.com/servlet/linkout?suffix=CIT0025&dbid=128&doi=10.1080%2F13691457.2018.1564736&key=000311692700008), , [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2012&pages=532-545&issue=4&author=V.+Foster&title=The+pleasure+principle%3A+Employing+arts-based+methods+in+social+work+research), p. 533) comments about the relevance of arts-based approaches,

(they) address power relations in the research process …  …  … .they facilitate empathy and challenge misconceptions by giving insight to their audience into aspects of their lives, revealing what their lives are like and the potential for how they could be.

The researchers had no more than one interview per session – with usually five running in parallel, with the project co-ordinating team on hand to support as necessary. Time was taken with both the ‘’ researchers and participants directly after each interview session to debrief. Feedback from the researchers about their experience of conducting the interviews was very positive, with some general comments about the experience;

‘Feeling nervous but once past the introductions the nerves went.’

‘‘The photos helped to get the conversation going’.

to more specific comments that throw light on the emotional impact for the researchers;

‘It was the best day of my life’

‘Enjoyable – I had a lot of laughs … ’

The first comment denotes the sense of achievement and level of confidence-building and sense of worth and value that the researcher, who had been a long-term mental health system survivor, had experienced through the training and the interviewing. The second comment, when explored further with the researcher, indicated a shared level of frustration, expressed through dark humour within the interview, which had had a therapeutic effect because it was shared. The researcher indicated a good level of self-awareness as she explored this issue.

**Data analysis**

Once the interviews had been transcribed, analysis days were arranged with the researchers, together as a group, to jointly identify initial codes and themes. The group discussed initial coding, sharing their own personal experiences, with some of their stories overlapping with those identified from the participants’ transcripts. As they worked together, a collective response to the data emerged from the group’s shared social model of disability (Oliver, [2009](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Oliver, M. (2009). *Understanding disability: From theory to practice* (2nd ed.). London: Palgrave Macmillan.[[Crossref]](https://www.tandfonline.com/servlet/linkout?suffix=CIT0034&dbid=16&doi=10.1080%2F13691457.2018.1564736&key=10.1007%2F978-1-137-05492-0), , [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2009&author=M.+Oliver&title=Understanding+disability%3A+From+theory+to+practice)) and developed a rich set of themes supported by the participants’ photos. A meeting with the participants to reality-check the findings with them and to add trustworthiness (Padgett, [2017](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Padgett, D. K. (2017). *Qualitative methods in social work research*(3rd ed.). London: Sage. [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2017&author=D.+K.+Padgett&title=Qualitative+methods+in+social+work+research), p. 92) concluded this part of the process.

The involvement of non-disabled researchers as ‘outsiders’ to the daily experiences of disabled people aided the process of reflexivity during this phase of the research. Rigour and integrity are important qualities to preserve in qualitative research where subjectivity (of the researcher(s)) and co-construction between researcher and participant are features of the research process. For this reason, researchers have to consider their positionality, in terms of their knowledge, experiences and beliefs, as well as the impact that the experience of doing the research has on them as researchers. Probst ([2015](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Probst, B. (2015). The eye regards itself: Benefits and challenges of reflexivity in qualitative social work research. *Social Work Research*, *39*(1), 37–48. doi: 10.1093/swr/svu028[[Crossref]](https://www.tandfonline.com/servlet/linkout?suffix=CIT0039&dbid=16&doi=10.1080%2F13691457.2018.1564736&key=10.1093%2Fswr%2Fsvu028), [[Web of Science ®]](https://www.tandfonline.com/servlet/linkout?suffix=CIT0039&dbid=128&doi=10.1080%2F13691457.2018.1564736&key=000350980600005), , [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2015&pages=37-48&issue=1&author=B.+Probst&title=The+eye+regards+itself%3A+Benefits+and+challenges+of+reflexivity+in+qualitative+social+work+research), p. 38) comments that ‘Reflexive researchers are, in essence, gazing in two directions at the same time.’ To support this process, the researchers, with the project co-ordination team, used activities such as debriefing, information-sharing and problem-solving through researcher journals (ie. ‘blogs’) and through group data analysis and member-checking with participants (Alston & Bowles, [2018](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Alston, M., & Bowles, W. (2018). *Research for social workers. An introduction to methods* (4th ed.). London: Allen and Unwin. [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2018&author=M.+Alston&author=W.+Bowles&title=Research+for+social+workers.+An+introduction+to+methods), p. 76).

Briefly, the following themes were identified across the interviews, revealing the reality of problems faced by disabled people within the built environment, on public transport, accessibility in public places like shopping centres and tourist attractions; housing and homes; car parks; public pathways; toilets; insensitive attitudes of other non-disabled people; difficulties within personal care relationships; exclusion from social spaces and education and sports establishments. These physical and attitudinal barriers impacted on disabled people’s quality of life and well-being, as they felt particularly that they did not have the same experience as non-disabled people in that they often felt their dignity was undermined through exclusion and having a ‘different’ experience. They had additional demands on their energy and stamina in order to confront barriers, which often resulted in a lack of spontaneity in aspects of their lives. This is not to say that there were no positive findings – some aspects of the built environment did provide good facilities for disabled people. The photographs and interview transcripts highlighted examples of good practice where organisations had provided accessible facilities including wheelchair accessible walkways in a country park. There was consensus that even when a business could not make reasonable adjustments to the facilities, a welcoming and understanding attitude to overcoming barriers had a positive impact on their overall experience and well-being.

**Dissemination**

The initial dissemination was a public exhibition of the photographs taken by the participants, held in the public space of the ground floor of the local university. As well as the general public, university staff and students, those who held power in the local authority on social care and planning issues were invited. Researchers and participants were involved in displaying the photographs, which were based on the data analysis themes of ‘what is working’ and ‘what could be better’, to emphasise the positive and negative findings of the project. To make the exhibition accessible for everyone, a podcast was made by the researchers and project co-ordination team and this was played throughout the exhibition and was particularly useful for visually impaired people. All the researchers were on hand to discuss their research. The exhibition of photos was especially important in profiling the continuing barriers experienced by disabled people throughout the county.

Reports were also written for the County Councils’ Strategic Equalities and Inclusion Board and the Coalition of Disabled People, but more importantly, in terms of raising public awareness, following on from the exhibition at the university an opportunistic/multi-level approach was taken to profile the project and to disseminate the findings of this pilot phase. Local libraries were used to display the exhibition as well as the ground floor of the County Council headquarters, where many county councillors are based.

**Local impact**

The impact of these exhibitions was noted when the researchers received local media attention and were invited to numerous planning projects taking place within the county, which included the ‘blue prints’ for the design of the new county records office, the design of an accessible walkway in a local forest, the facilities for disabled access in a local zoo and a visitors’ centre. Additionally, the researchers were invited to comment on town centre planning for two towns in the county.

**Evaluating the pilot project**

It was important for the project coordination team and the Coalition to be clear about the benefits and challenges before expanding the research further. To this end, feedback was obtained during the pilot, from both researchers and participants, in various ways. Two significant platforms for this were the quality of the relationships forged during the pilot phase, which built trust and respect from an exchange of expertise, and the support this engendered, which produced an open exchange of views and feedback for evaluation purposes.

**Collaboration and expertise**

The rapport between the project coordination team and the researchers was established very early on during the selection process and training sessions. The project coordination team was very keen to build a collaborative culture from the start and a shared learning experience for all involved in the project. The non-disabled members brought expertise about research methods and the disabled researchers brought expertise about disability and everyone's openness to learning created a cooperative non-hierarchical learning environment. This is not to say that the project coordinators did not have some anxieties about engaging researchers with no previous experience, apart from the five training sessions offered. However, the passion, openness and enthusiasm within the group carried the project forward and instilled determination to lend rigour and quality to the project. Early in the process, the researchers developed a reflective space via a blog, in which they shared their learning from the teaching sessions and the interviews in order to monitor progress. This space was actively shared with the disabled member of the project co-ordination team and then with the other two researchers from the local authority and university. Through this online space, ongoing researcher self-evaluation during the process and evaluation of the pilot could be maintained.

**Emotion work and support**

The evaluation involved intellectual consideration of the methods used and their relevance to the data being collected and analysed. The experiences of the researchers, as the pilot phase progressed, confirmed the original decision to use a qualitative methodology and PAR methods, often used in this type of research (Aldridge, [2014](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Aldridge, J. (2014). Working with vulnerable groups in social research: Dilemmas by default and design. *Qualitative Research*, *14*(1), 112–130. doi: 10.1177/1468794112455041[[Crossref]](https://www.tandfonline.com/servlet/linkout?suffix=CIT0001&dbid=16&doi=10.1080%2F13691457.2018.1564736&key=10.1177%2F1468794112455041), [[Web of Science ®]](https://www.tandfonline.com/servlet/linkout?suffix=CIT0001&dbid=128&doi=10.1080%2F13691457.2018.1564736&key=000329435600007), , [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2014&pages=112-130&issue=1&author=J.+Aldridge&title=Working+with+vulnerable+groups+in+social+research%3A+Dilemmas+by+default+and+design)), and these allowed for effective engagement with the participants and also confirmed the proficiency of the researchers. Additionally, the team considered the emotional impact of the research on the researchers and participants, as highlighted earlier, and, in taking into account this ‘emotion work’ (Hochschild, [1983](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Hochschild, A. (1983). *The managed heart: The commercialisation of human feeling*. Berkeley, CA: University of California Press. [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=1983&author=A.+Hochschild&title=The+managed+heart%3A+The+commercialisation+of+human+feeling)), encouraged its expression and understanding, which contributed to the feedback and evaluation.

This recognition of emotion work is particularly important when researching ‘sensitive topics’ with ‘vulnerable groups’ (Dickson-Swift, James, Kippen, & Liamputtong, [2009](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Dickson-Swift, V., James, E. L., Kippen, S., & Liamputtong, P.(2009). Researching sensitive topics: Qualitative research as emotion work. *Qualitative Research*, *9*(1), 61–79. doi: 10.1177/1468794108098031[[Crossref]](https://www.tandfonline.com/servlet/linkout?suffix=CIT0020&dbid=16&doi=10.1080%2F13691457.2018.1564736&key=10.1177%2F1468794108098031), [[Web of Science ®]](https://www.tandfonline.com/servlet/linkout?suffix=CIT0020&dbid=128&doi=10.1080%2F13691457.2018.1564736&key=000272880000003), , [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2009&pages=61-79&issue=1&author=V.+Dickson-Swift&author=E.+L.+James&author=S.+Kippen&author=P.+Liamputtong&title=Researching+sensitive+topics%3A+Qualitative+research+as+emotion+work)). The interactions between the researchers and the participants produced shared emotions, for example, about the experience of a disabling environment, but also the researchers revealed, in their comments about their experience of being researchers, e.g. their lack of confidence at times, or their pleasure, pride and elation in being involved. As one researcher commented, his first interview day was ‘the best day of my life’. The location of the meetings and interviews in the university was an important contributing factor to the increase in confidence for the researchers, and was proudly viewed as a confirmation of their worth. The processing of these feelings involved the project co-ordination team and the researchers themselves, through meetings, blogs and telephone contact, and importantly was characterised by mutuality and reciprocity as well as reflexivity (Stanley & Wise, [1983](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Stanley, L., & Wise, S. (1983). *Breaking out: Feminist consciousness and feminist research*. London: Routledge and Kegan Paul. [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=1983&author=L.+Stanley&author=S.+Wise&title=Breaking+out%3A+Feminist+consciousness+and+feminist+research)).

Such processes aided the evaluation of the pilot project as reported on here. The blogs provided a shared reflective space, as did the training sessions and data analysis meetings. Further comments were shared in emails, individual and group discussion between the disabled member of the project coordination team and the researchers, who all maintained contact as the pilot continued through to the dissemination phase. This all provided material for this evaluation and ensured that the essentially unified voices of the ’ researchers were captured.

**Benefits**

**Credibility and trustworthiness**

As stated earlier, the commitment from all involved in the project was strengthened by the shared value base. It was important to maintain this throughout so that the joint exercise of a PAR project could yield credible and convincing results that would promote the transformative aim (Aldridge, [2014](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Aldridge, J. (2014). Working with vulnerable groups in social research: Dilemmas by default and design. *Qualitative Research*, *14*(1), 112–130. doi: 10.1177/1468794112455041[[Crossref]](https://www.tandfonline.com/servlet/linkout?suffix=CIT0001&dbid=16&doi=10.1080%2F13691457.2018.1564736&key=10.1177%2F1468794112455041), [[Web of Science ®]](https://www.tandfonline.com/servlet/linkout?suffix=CIT0001&dbid=128&doi=10.1080%2F13691457.2018.1564736&key=000329435600007), , [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2014&pages=112-130&issue=1&author=J.+Aldridge&title=Working+with+vulnerable+groups+in+social+research%3A+Dilemmas+by+default+and+design), p. 124). One aspect of this joint enterprise was the reflexivity developed by the group, as discussed above, which contributed to the trustworthiness of the findings.

The use of photographs meant empathy was established very quickly in the interviews between the researchers and the participants, and shared experiences identified. Reinharz ([1979](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Reinharz, S. (1979). *On becoming a social scientist*. San Fransisco: Jossey-Bass. [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=1979&author=S.+Reinharz&title=On+becoming+a+social+scientist)) highlights the benefits of intersubjectivity, which help with the establishment of emotional connection and empathy in the process of human research, and the engagement of the researchers with the participants demonstrated a passion and commitment to the project as a result. It became important, however, in the data analysis, to ensure that this passion and commitment did not prevent the researchers from seeing the results from an un-assumed perspective, so for this reason it was important to establish a questioning and reflexive process in the data analysis meetings to ensure that new knowledge was not overlooked.

The use of photographs produced clear visual evidence to support the verbal comments of the participants and helped to *‘*overcome the challenges of third-party interpretation because, in some cases, this kind of evidence can simply ‘speak for itself’ (Aldridge, [2014](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Aldridge, J. (2014). Working with vulnerable groups in social research: Dilemmas by default and design. *Qualitative Research*, *14*(1), 112–130. doi: 10.1177/1468794112455041[[Crossref]](https://www.tandfonline.com/servlet/linkout?suffix=CIT0001&dbid=16&doi=10.1080%2F13691457.2018.1564736&key=10.1177%2F1468794112455041), [[Web of Science ®]](https://www.tandfonline.com/servlet/linkout?suffix=CIT0001&dbid=128&doi=10.1080%2F13691457.2018.1564736&key=000329435600007), , [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2014&pages=112-130&issue=1&author=J.+Aldridge&title=Working+with+vulnerable+groups+in+social+research%3A+Dilemmas+by+default+and+design), p. 122).

**Voice and agency**

The touring exhibition for dissemination of the findings provided the researchers with a platform to illustrate the participants’ stories through the photographs and represent a truth of experience that was rich in detail and convincing in representation of lived experience through words and through the significance of the photographic evidence. The project co-ordinating team observed how much the researchers enjoyed this aspect of the research.

As discussed earlier, disability research emphasises the crucial importance of effective change arising from research findings, so it is important that research outcomes are not tokenistic. The action research approach provided researchers and participants with the opportunity to have their voices heard and to have agency in achieving change for disabled people locally. Involvement in the planning stages also meant that the ‘voices’ of all researchers were heard and acted upon, not just those with the loudest voice or most ‘obvious’ disability demanding change.

**Skills development and resilience**

The increased resilience of the researchers was noticeable in the ‘action for change’ phase. This benefit has been noted elsewhere (Macpherson, Hart, & Heaver, [2016](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Macpherson, H., Hart, A., & Heaver, B. (2016). Building resilience through group visual arts activities: Findings from a scoping study with young people who experience mental health complexities and/or learning difficulties. *Journal of Social Work*, *16*(5), 541–560. doi: 10.1177/1468017315581772[[Crossref]](https://www.tandfonline.com/servlet/linkout?suffix=CIT0031&dbid=16&doi=10.1080%2F13691457.2018.1564736&key=10.1177%2F1468017315581772), [[Web of Science ®]](https://www.tandfonline.com/servlet/linkout?suffix=CIT0031&dbid=128&doi=10.1080%2F13691457.2018.1564736&key=000382470300002), , [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2016&pages=541-560&issue=5&author=H.+Macpherson&author=A.+Hart&author=B.+Heaver&title=Building+resilience+through+group+visual+arts+activities%3A+Findings+from+a+scoping+study+with+young+people+who+experience+mental+health+complexities+and%2For+learning+difficulties)). In particular, the researchers built on the confidence they gained from the interviewing and analysis, by further developing confidence in interacting with the public and feeling ‘heard’.

Additionally, the experiences that the project has provided for the researchers and participants in drawing on and extending their skills and abilities has had a positive impact on their personal lives. Several researchers and participants have reported that since being involved in the research they have applied for jobs and one of the participants has become a school governor as the result of their increased sense of self-confidence and self-efficacy.

**Challenges**

**Researcher positioning and inter-subjectivity**

Like feminist methodology and feminist standpoint theory and research (Stanley & Wise, [1983](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Stanley, L., & Wise, S. (1983). *Breaking out: Feminist consciousness and feminist research*. London: Routledge and Kegan Paul. [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=1983&author=L.+Stanley&author=S.+Wise&title=Breaking+out%3A+Feminist+consciousness+and+feminist+research)), which place significance on the particular capacity of female researchers to understand other women, so this research emphasised the importance of using disabled researchers who could understand the experiences of other disabled people. However, shared empathy between each researcher and participant, who are peers, with very similar and sometimes painful experiences of, in this case, social exclusion may raise ethical issues about the emotional protection of those involved. So, to address this, the emotional responses of each were monitored and supported following the interviews by the members of the research co-ordinating team who were available throughout.

Inter-subjectivity may also lead to over-identification between researcher and researched. Accordingly, we ensured space during the data analysis sessions, held with the project co-ordinating team and the researchers together, to think as a group. We considered the feelings triggered in the researchers by the experiences, attitudes and beliefs of the participants, and their impact on the researchers, to encourage critical self-awareness through reflexivity (Payne & Payne, [2004](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Payne, G., & Payne, J. (2004). *Key concepts in social research*. London: Sage.[[Crossref]](https://www.tandfonline.com/servlet/linkout?suffix=CIT0036&dbid=16&doi=10.1080%2F13691457.2018.1564736&key=10.4135%2F9781849209397), , [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2004&author=G.+Payne&author=J.+Payne&title=Key+concepts+in+social+research), pp. 191–195).

The process of data analysis raised issues for the project co-ordination team in terms of the researchers’ ‘insider’ position. As disabled researchers sensitised to physical and attitudinal barriers within society, they might have over-identified with the disabled participants with a ‘taken for granted’ approach within the interviews. Alongside this, there was concern, particularly during data collection, about whose story might dominate within the interviews – that of ‘the researcher’, or ‘the participant’, due to shared experiences. This was highlighted when one of the researchers fed back about their interviewing experience: ‘Enjoyable – I had a lot of laughs … ’*.* This might have indicated a blurring of boundaries and collusion within the interviews. However, whilst the transcripts identified commonalities, nevertheless the voice of the participant clearly came through and this was supported by the photographs. The ‘outsider’ perspective of the non-disabled members of the research team also aided reflection within the analysis process, adding a potentially counter-balancing effect, through open and honest questioning in the discussions. The project co-ordinators attempted to mitigate this by alerting the researchers during the training sessions and developing a reflexive and questioning approach during the data analysis meetings.

**Challenges to parity of status**

The role of the project co-ordinating team was potentially problematic. Arnstein’s Ladder of Participation ([1971](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Arnstein, S. (1971). A ladder of citizen participation. *Journal of the Royal Planning Institute*, *35*(4), 216–224. [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=1971&pages=216-224&issue=4&author=S.+Arnstein&title=A+ladder+of+citizen+participation)) has been mentioned earlier, with the aim of positioning the project on the top rung – citizen control. As Aldridge ([2014](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Aldridge, J. (2014). Working with vulnerable groups in social research: Dilemmas by default and design. *Qualitative Research*, *14*(1), 112–130. doi: 10.1177/1468794112455041[[Crossref]](https://www.tandfonline.com/servlet/linkout?suffix=CIT0001&dbid=16&doi=10.1080%2F13691457.2018.1564736&key=10.1177%2F1468794112455041), [[Web of Science ®]](https://www.tandfonline.com/servlet/linkout?suffix=CIT0001&dbid=128&doi=10.1080%2F13691457.2018.1564736&key=000329435600007), , [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2014&pages=112-130&issue=1&author=J.+Aldridge&title=Working+with+vulnerable+groups+in+social+research%3A+Dilemmas+by+default+and+design), p. 123) comments: ‘the top-of-the-ladder participatory research aspiration would seem to leave little room for the role of the professional researcher other than that of the ‘critical friend’ or advocate perhaps.’ Dzur’s ([2008](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Dzur, A. W. (2008). *Democratic professionalism. Citizen participation and the reconstruction of professional ethics, identity and practice*. University Park, PA: The Pennsylvania State University Press. [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2008&author=A.+W.+Dzur&title=Democratic+professionalism.+Citizen+participation+and+the+reconstruction+of+professional+ethics%2C+identity+and+practice), p. 105) position differs slightly, viewing professionals as facilitators, which was a more accurate description of how the two professionals of the project co-ordinating team shared their expertise in the training sessions. This, along with the shared value commitment to PAR, the mutual respect of all involved and the significance placed on reflexivity throughout the pilot project, meant that any challenges to parity of status within the project were overcome.

**Diversity and representativeness**

One of the issues raised in challenging the scope of the project is that of a lack of diversity and representativeness within the researcher group. The researchers initially included two people with mental health difficulties. One withdrew before the interview stage, due to a recurrence of these difficulties – a potential risk for some users of mental health services. There was also a visually impaired participant, but on the whole most researchers and participants experienced physical disabilities. This was an area of challenge for the project co-ordinating team as the researchers, like the participants, were recruited via advertising, and so were self-selecting. Had the advertising been framed differently, for example by using an ‘easy read’ format or pictures, then people with learning disabilities may have responded. This would have prompted a different approach to the training and might have involved advocates. The Coalition’s membership was largely made up of people with physical disabilities so this is the population from which we drew interest. However, this lack of diversity has influenced the nature of the findings. Similarly, all the researchers were white British and there was no ethnic diversity, though there was more balance in relation to gender. The limited range of disabilities represented across the participants can be viewed as limiting the issues explored, particularly for disabled people, where intersectionality is an additional issue, for example, disability and ethnic diversity, sexual orientation etc. The project team decided to go ahead as this was a small pilot project – a risk we took in order to test the methodological approach – but in the future expansion of the project we would seek to actively engage a wider representation in order to increase the relevance of the ‘voice’ of those marginalised by disabling attitudes and environments.

**Conclusion**

The preceding discussion has demonstrated how a co-productive approach to the research and the action research application of its findings have increased the voice and profile of disabled people in the local area, though with some limitations. The group of disabled researchers came together to combine their expertise as ‘insider researchers’ with that of the participants, to produce a collective ‘story’, facilitated by the expertise of professionals with a shared value base. This produced a combined strength that has become a force for change both at an individual and at a collective level. For individuals, their increased skills base is transferrable to other areas of their lives as well as in their organisation. The close collaboration between all involved, based on trust, mutuality and recognition of inter-dependence and the substantial resource contribution of all involved, demonstrates the effectiveness of a co-productive approach in influencing change. As a consultancy group, the ‘’ researchers have been able to influence the need for change in services and the targeting of resources. Whilst in this instance it has, in the main, serviced a need to challenge the persistence of physical and attitudinal barriers for disabled people which affect their quality of life, it also points to the need for this approach to be the norm in the planning and provision of services.

As a challenge to the bureaucratisation of public services under managerialism (Rogowski, [2010](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Rogowski, S. (2010). *Social work. The rise and fall of a profession?*Bristol: Policy Press.[[Crossref]](https://www.tandfonline.com/servlet/linkout?suffix=CIT0043&dbid=16&doi=10.1080%2F13691457.2018.1564736&key=10.2307%2Fj.ctt9qgp2q), , [[Google Scholar]](http://scholar.google.com/scholar_lookup?hl=en&publication_year=2010&author=S.+Rogowski&title=Social+work.+The+rise+and+fall+of+a+profession%3F), [2013](https://www.tandfonline.com/doi/full/10.1080/13691457.2018.1564736?scroll=top&needAccess=true)Rogowski, S. (2013 April 4) What is the way forward for social work? *The Guardian.*Retrieved from<https://www.theguardian.com/social-care-network/2013/apr/03/way-forward-for-social-work>. [[Google Scholar]](http://scholar.google.com/scholar?hl=en&q=Rogowski%2C+S.+%282013+April+4%29+What+is+the+way+forward+for+social+work%3F+The+Guardian.+Retrieved+from+https%3A%2F%2Fwww.theguardian.com%2Fsocial-care-network%2F2013%2Fapr%2F03%2Fway-forward-for-social-work.)), this way of working offers a much more enlightened and democratic approach to the relationships between users of services and professionals in the planning and delivery of welfare services, at all levels, and offers a template for researchers, organisations and practitioners in using a strengths-based and relationship-based approach to the promotion of dignity and well-being in engaging with the users of services.

**Disclosure statement**

No potential conflict of interest was reported by the authors.

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***Geof Dix*** For the period of the research, ***Geof Dix*** was a Disability Development Officer for the Suffolk Coalition of Disabled People, which is an organisation in Suffolk run for and by disabled people. It is concerned with promoting disabled people's rights and well-being. Geof has a disability and his expertise about disability issues was invaluable in the organisation of this research project.

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