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Co-producing Community with Disabled Researchers and Citizens: the Challenges and Potential for Successful Collaboration

Abstract

The chapter discusses the development of a collaborative research project, involving a service user-led Coalition of Disabled People, a local authority and a local university. The collaboration was set up to inform the Coalition's strategic planning and to raise awareness of disability issues locally, mapping assets and resources for/of disabled people, as well as needs and resource gaps. The initial pilot of this "listening project" is critiqued here. It adopted an inclusive approach to the differing roles and competences within the project co-ordinating team, whose members worked together to recruit and train disabled researchers and engage a small sample of participants. The project drew on ideas from emancipatory disability research to inform its approach. The discussion evaluates the benefits and challenges of a collaborative approach to data collection, analysis and dissemination of findings, to achieve meaningful change locally, critically reflecting on praxis and the project's effectiveness.

Introduction

This contribution will critique the development of a collaborative research project, involving a service user led Coalition of Disabled People, a local authority and local university within the eastern region

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of England. The project was set up to inform the Coalition's strategic planning and to raise awareness of disability issues locally, mapping assets and resources for/of disabled people as well as needs and gaps. The following discussion will look critically at why and how the research developed as a collaborative project between the Coalition, the university and the local authority. It will critically explore some of the issues that arose as the project progressed and in particular will examine the tensions and benefits of recruiting and training local disabled people to conduct the research interviews, to be part of the process of analysing the data, incorporating their contribution as insider researchers and as "experts by experience". Findings from the research are considered along with the importance of acting on these to achieve the desired impact of promoting change.

Historical context of disability research

Historically, disability research has arisen out of a critique of mainstream research that was seen to serve the (mainly able-bodied) researchers more than the disabled people being researched (Oliver, 1992). Mike Oliver offered this critique within a wider discussion and theorising about the position of disabled people in Western society, in which a number of disabled scholars were debating the relative significance of impairment and disability, with some, for example disabled feminists such as Jenny Morris (1992), placing an emphasis on the personal experience of impairment, whilst others were exploring the sociological aspects of disablism (e.g. Oliver, 1996; Barnes, 1998). The interconnectedness of impairment and disability, and the effects of the one on the other within social, cultural and material contexts were also theorised (Thomas, 1999). Goodley (2017) provides a useful summary of the different strands within the development of disability theory. Disability research, like feminist research that draws on Feminist Standpoint Theory (Stanley, Wise, 1983; Ramazanoglu, 2002) has a particular "world view" which is that the central focus is on disabled people and their concerns, that research should be done with and not to them, and that the outcomes should be beneficial for disabled people. The aim is to capture their lived experience, listen to their stories and influence change, through a "lens" that sees the social construction of disabled people as oppressive. Again, there is a parallel with feminist research methodology, with its emphasis often on the subjective, using a qualitative approach that is flexible, to embrace the detail of peoples lives.

Research context and problem identified

The Suffolk Coalition of Disabled People (SCODP) was set up in 2013 as the first organisation of its kind in Suffolk – i.e. a service user-led organisation for people with a range of disabilities, as part of the growing development of organisations that were led by disabled people for disabled people based on the “nothing about us without us” slogan which refers to the influence that disability activism seeks over policy making (Charlton, 1998). As a newly established organisation, SCODP required a knowledge base from which to represent members and to lobby and campaign collectively for appropriate resources and services. Within this context, the research needed to be developed to ensure that it was co-productively executed, according to the top rung (citizen control) of Arnstein’s Ladder of Participation (Arnstein, 1971).

To this end, it required a research strategy to establish the numbers of disabled people within the county, to ascertain what resources existed already in Suffolk for disabled people and what the gaps were in terms of disabled people’s needs and wishes to enable them to participate within their communities and to achieve dignity and well-being in their lives.

Conversations between representatives from the Coalition, the University of Suffolk and Suffolk County Council (SCC) Adult and Community Services produced a research plan that involved a three-pronged scoping exercise to:

- determine the numbers of disabled people across the county (from existing SCC statistics held by the Insight and Intelligence Team);
- provide an overview of existing resources through a telephone audit, using Coalition members to provide information about services they had used/were using, and;
- 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.

This initial reflective and early planning phase of the project took place in late 2014 and stage 2 of the project began with the telephone audit of services in the spring/summer of 2015, supported by social work students on placement at the Coalition who were supervised through the University. Funding was achieved to extend the project and research governance approval was obtained.

On examination of the data available for the rural county of Suffolk in the Eastern region of England, the following highlights were acknowledged.

Suffolk County has a total population of 741,895 (ONS 2015 mid-year population estimate) of which 18% are aged 0–15; 15% 16–29; 17% 30–45; 27% 45–64 and 22% 65+.

Table 1. Suffolk people aged 18–64 predicted to have a moderate or serious physical disability or common mental health disorder projected to 2018

	2014	2015	2016	2017	2018
Total population aged 18-64 predicted to have a moderate physical disability	34 609	34 641	34 786	34 923	35 056
Total population aged 18-64 predicted to have a serious physical disability	10 425	10 436	10 497	10 559	10 625
People aged 18-64 predicted to have a common mental disorder	68 423	68 359	68 359	68 352	68 307
Figures may not sum due to rounding. Crown copyright 2014					

Source: www.pansi.org.uk version 8.0 (accessed: 08.05.2107).

Table 2. Suffolk people aged 18–64 predicted to have a moderate or serious physical disability or common mental health disorder projected to 2030

	2014	2015	2020	2025	2030
Total population aged 18-64 predicted to have a moderate physical disability	34 609	34 641	35 310	35 579	34 890
Total population aged 18-64 predicted to have a serious physical disability	10 425	10 436	10 779	11 011	10 767
People aged 18-64 predicted to have a common mental disorder	68 423	68 359	68 196	68 026	67 398
Figures may not sum due to rounding. Crown copyright 2014					

Source: www.pansi.org.uk version 8.0 (accessed: 27.04.2017).

The research

There were a number of factors shaping the research approach, which was co-produced initially by the three organisations and this co-production continued when the expert researchers and co-researchers were recruited. Firstly, the social model of disability informs the work of Suffolk Coalition of Disabled People, which challenges structural exclusion, which led to the research being based on the social model as promoted by disability researchers such as Colin Barnes (1998) and Mike Oliver from a materialist perspective (1996) (see earlier).

In addition, the influence of developmental research (linked to Co-operative (person-centred) Inquiry (Heron, 1996)) and the standpoint theory from feminist research (Stanley, Wise, 1983; Ramazanoglu, 2002) was drawn on, in the sense that there should be transformative benefits for all involved in the research project. Emancipatory Disability Research, (arising out of the Disability Movement in the UK from the 1970s onwards), challenges the historical dominance of the medical model and academic research in Disability Studies, and states that, to challenge exclusion, research must be with disabled people as active participants and fellow researchers, based on the social model (a socio-political interpretation of disability and disability as social oppression).

A collaborative approach combining different kinds of knowledge and expertise was therefore required – pulling together the lived experience and knowledge of disability from disabled people themselves and the expertise of experienced researchers with their knowledge of project management, research theory and research experience. This would promote and enable collaborative learning for all involved. To this end, therefore, an emancipatory approach was developed (Goodley, 2017: 29). This approach to research problematises power and control within research relationships, aiming to equalise the research relationship, hence the significance of expert researchers and expert participants (co-researchers). As stipulated by Michael Turner and Peter Beresford (2005), the research project was initiated by the Suffolk coalition – i.e. by disabled people themselves, and was underpinned by a set of values that included 'empowerment, emancipation, participation, equality (and) anti-discrimination' which continued throughout the research process (Turner, Beresford, 2005: 27). This meant that for this stage of the project, disabled people would be recruited as expert researchers and participants as co-researchers, each drawing on their experiences as disabled people and as "insiders" (Robson, McCartan, 2016: 399) with lived experience of and expertise in the problems identified for exploration. It was also important that all were involved in the analysis and dissemination of the findings.

Key characteristics of this approach, according to Colin Barnes (2003) are:

- accountability to organisations controlled and run by disabled people (SCODP);
- a commitment to the social model of disability;
- the choice of methodology and methods tend to be qualitative;
- meaningful practical outcomes for disabled people.

The project was developed with all these factors in mind.

Project aims and objectives

The aim was to develop a clear understanding of the demand for current and future disability services across the county of Suffolk, building on an initial audit of existing services conducted by SCODP in 2015. The objectives were:

– for disabled people in Suffolk to identify the issues most pressing for disabled people – what works and what does not work in their lives;
– to gain a better understanding of what it is like to be a disabled person living in Suffolk, through engaging disabled researchers who have “insider” knowledge;
– to support and train Expert Researchers who are disabled or are affected by long-term health conditions to undertake the research with their greater understanding of disability issues.

Project planning

As SCC’s Adult and Community Services already held quantitative information on the support they provide in the community to current customers, this third phase of the project entitled the Expert Researchers Project, aimed to undertake qualitative interviews across the county to capture the real experience of living in Suffolk with a disability. A pilot project would initially be in Ipswich. The Project Co-ordinating Team comprising a representative from each of the three organisations – Suffolk County Council, the Suffolk Coalition of Disabled People and the University of Suffolk, held regular meetings to plan the stages of the research, put together a research governance application, recruit (job description, advertising and selection process) and train (5 training sessions on qualitative interviewing) expert researchers, organise the selection of the participants (co-researchers), track funding applications and monitor spending, set up the interviews, and arrange the data analysis sessions (carried out together by the expert researchers with the project team). This was all done to achieve the following outcomes:

– that the voices of disabled people can be heard and have influence;
– that future Health and Social Care services commissioned can more accurately reflect the needs of people and carers in Suffolk communities;
– that services that are timely and effective will target demand more accurately with the possibility of reducing costs in the future.

Methodology

When considering the methodology, the quantitative information already available was examined, and the need for more qualitative data from customers living in local communities who were using services and accessing a range of resources and facilities was identified, as stated above. The co-produced methodology for stage 3 therefore sought to undertake qualitative interviews via expert researchers with co-researchers capturing the real experience of living in Ipswich (initial pilot) with a disability. It was additionally decided to equip co-researchers with a disposable camera to record their experiences. These images were used to inform the qualitative, semi-structured interviews.

This approach has connections with an approach to using photographs within qualitative interviews, which has been termed a "photo elicitation method" (Harper, 2002). Douglas Harper (2002: 20) describes this method mainly from the point of view of researchers presenting participants with photographs, in which "photo elicitation may overcome the difficulties posed by in-depth interviewing because it is anchored in an image that is understood, at least in part, by both parties".

He also discusses a study in which the method is used with participants who self-interview. He also 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: 23).

Recruitment and training

Researchers and co-researchers were recruited using SCODP's networks and local media. Researchers and co-researchers self-selected. For this pilot phase we were not able to include people with a range of disabilities as numbers were small (5 researchers and 10 co-researchers). 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 expert researchers and co-researchers that the recruitment and training sessions would be held in accessible spaces and any barriers to attendance would be removed. A fun and relaxed recruitment day was held to assess the skills of the potential expert researchers in relationship-building and empathy. This time together was also an opportunity to develop the five training sessions around using the shared knowledge of the expert researchers.

Data collection

An integral part of the weekly training sessions was the shared learning and development of everyone involved in the project. Feedback was given to the trainers via a weekly blog with each expert researcher in turn writing a blog to summarise the training session. These blogs were helpful reminders of the knowledge shared and an effective tool when absence from a training session was unavoidable. The final two training sessions were used to develop and practice the research questions in preparation for the interviews. Finally, a session was held to introduce expert researchers to the co-researchers they would interview and to distribute disposable cameras for the co-researchers to record images of their daily experiences. 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. The pictures supported the transcripts recorded by the Co-researchers and were later displayed for public viewing and comment (see Dissemination below).

Interviews and thematic analysis

Time was taken with both the expert researchers and co-researchers directly after each interview session, coming together to discuss and share experiences. As these quotes demonstrate the feedback was positive:

> Feeling nervous but once past the introductions the nerves went.
> Enjoyable – I had a lot of laughs…
> It was the best day of my life
> The photos helped to get the conversation going.

All the interviews were recorded, and once transcribed, analysis days were arranged with the expert researchers to identify initial codes and themes jointly as a group. The group discussed the initial coding, sharing their experiences, with many of their stories overlapping with those identified from the co-researcher transcripts. Working together the group seemed to naturally develop a collective response to the emerging issues and a shared set of values emanating from a social model perspective (Oliver, 2009), characterised the way the data was interpreted.

During these reflective discussions, larger themes were identified and presented to both the expert researchers and co-researchers to reality-check the findings.

The following themes were identified as areas for discussion, and most of these themes were identified by more than one co-researcher, emerging as common themes, revealing problems for disabled people in the following areas, as listed below:

- Built Environment – eg. uneven pavements for visually impaired people and wheelchair users;
- Transport – having to wait to access a bus with space for a wheelchair – especially when parents with prams/buggies are also competing for the space. Having to plan a train journey with advanced notice to stations for the use of ramps for wheelchair access;
- Accessibility – Shops – e.g. steps in shops in Ipswich town centre which prevent wheelchair users from accessing all areas of the shop, or display materials that block aisles, or outside pavements and prevent or limit access;
- Housing/Homes – the difficulties of obtaining timely assessments and the work being scheduled. The work can take up to a year for the recommended adaptations to be completed. As councils prioritise rent over suitability;
- Car Parks – e.g. lift not operating on Sundays in one car park which bars wheelchair users on that day;
- Pathways in public open spaces - e.g. some have steps which prevent wheelchair users from accessing the paths;
- Services – Care packages not being tailored to the person and care being offered at times more convenient to the care provider rather than the customer. Wheelchair users not having the same experience as non- disabled people – i.e. cinema;
- Attitudes – cars parked on the pavement which cause wheelchair users to move into the road with risk to themselves and other road users;
- Toilets – insufficient disabled toilets in public spaces;
- Personal Care/Relationships - Difficulty in obtaining the correct type of care and trust in person/company obtaining care package from. Selection of carers limited and process complicated. Being limited in how we take care of ourselves, correct equipment and facilities to allow personal care especially in public places. Relationships with public and perceptions of what disabled people look for in a relationship i.e. other disabled people or no relationship at all;
- Social Exclusion – Being excluded from major events due to lack of space for disabled or facilities not suitable. Perception of disabled people not wanting to voice opinions therefore being excluded from given choice;
- Education – Choice of subjects and facilities, if the venue is not accessible. What’s on offer to disabled people and special requirements through the course, is there enough special education for non-disabled to understand the complex needs for disabled people wanting further education. Need for more disabled teachers to be trained and encouraged to teach;

- Risk – Vulnerability when out alone, risk of falls and lack of public help. Risk of being "scammed" due to lack of education regarding these issues and confidence to stand up for themselves;
- Sports – Choice of sports for disabled people, transport, especially if rural, costs including transport, changing facilities not being adequate, trained staff to teach the sports to the disabled. More sports are coming up for disabled people but time, cost, special training and facilities stop people from attending. Promotion of sports for disabled people not nationwide or local to various areas.

These initial themes were grouped together to form more general themes, which included:

- Built environment and accessibility;
- Transport;
- Attitudes (to self and of others);
- Social Exclusion;
- Financial issues;
- Technology;
- Work;
- Personal care/relationships;
- Risk;
- Frustrated independence;
- What works and why?

Together we developed some overarching themes which linked across those listed above. These highlighted the experiences of disabled people across all areas of life and in their engagement with others, and serve to indicate how physical barriers and negative experiences (e.g. attitudes of others) can have an impact on mental health and well-being. These were:

- Quality of life/well-being;
- Wanting the same experience as everyone else;
- The additional demands on a disabled person's energy to confront barriers;
- The undermining of dignity;
- The lack of spontaneity in aspects of disabled people's lives.

Research in action – the challenges

As discussed earlier, the commitment to social justice as an outcome for the research project meant that methodologically, we were working within the emancipatory research paradigm. As Mary Swigonski (1994: 390) stated in relation to feminist research, insider researchers have "a knowledge of, awareness of, and sensitivity to both the dominant worldview of society and their own perspective".

This is the basis of the expertise that "experts by experience" bring to the research process, and in conjunction with the participants are thereby able to make visible the issues under investigation, which in everyday life are barely in view for the majority who structurally occupy a different position. Discussions with our expert researchers prior to conducting the interviews highlighted that they felt that self-disclosure within the research interviews was inevitable due to the likely similarity of experiences of physical and attitudinal barriers within everyday experiences of disabling environments, as well as positive experiences. This made explicit their "standpoint". In conventional research, this kind of social process for generating the data would be seen as "contamination", as it moves away from the notion of the scientifically neutral and objective "outsider" researcher, studying subjects external to her/himself. This blurring of boundaries between researcher and researched in collaborative research can raise issues about the validity of the research, but this is countered by arguments that suggest that positivist research itself cannot be bias-free (Crotty, 1998), that critical social research is "an essentially political activity rather than a neutral fact-finding mission" (Beresford, 2002: 99), and that the less distance there is between the experience and its interpretation, then the more accurate it is likely to be (Beresford, 2003).

Shulamit Reinharz (1995) highlights benefits from this research approach, when she refers to the passion and commitment that arises in human research when subjectivity lends itself to the establishment of empathy through emotional connection and inter-subjectivity. In our research, the sharing of concrete experiences, supported by the use of photographs of these experiences, formed a firm basis for the interviews and data collection. One of the researchers commented during a reflective session after an interview day that she "had a lot of laughs". Expanding on this in the group discussion, it was clear that some of the laughs were a way of dealing with issues that were serious or sad around shared experiences of oppression. This illustrated the "insider" identification that can promote trust and security within the research relationship, reducing the need for "impression management" and the fear of being judged on what one shares, so that the participant feels able to speak and share openly and honestly.

However, as Heather D'Cruz and Martyn Jones (2014: 110) comment, there is a "shifting combination" between insider and outsider identities, and a combination of both can occur along a continuum. In relation to this research project, the "insider" researcher, through participation in reflective discussions, had to stand back and take a more outsider position to think critically about "taken for granted" realities and positions to avoid the danger within this approach, of what Kate van Heugten (2004: 207) refers to as the “spectre of insider bias”. Discussing “nearness” as an issue between researcher and participant, Jones (2004) warns of the dangers of what she terms “peerness” – i.e. the problems of similarity of experience for peer researchers when there can be difficulty separating participants’ responses about their experiences, from their own, as researchers. To recognise and be vigilant about this possibility, there was a need for constant examination and challenging of existing knowledge and beliefs to ensure an openness to new knowledge, rather than overlooking it due to being close to the lived experience. This openness was important in this research project, because insider positioning and expertise can not only cause the unquestioning acceptance of information as taken-for-granted, but can also underplay its significance, as much as outsider positioning can fail to explore and acknowledge important issues because of a lack of detailed knowledge and experience.

An added dimension to this is that the expert researchers and the participants or co-researchers could not claim representativeness within their communities. Whilst both groups were what Hugh McLaughlin (2010: 1594) terms “direct” service users’ – i.e. at the time of the research, using the services and managing their lives in the area under investigation, and they were physically disabled as wheelchair users or with a sensory impairment, or with a mental health diagnosis (past or present), there was no guarantee that their experiences were going to completely overlap with those of the wider community. Both groups were self-selecting, because they were motivated to be actively involved in a process of change, but due to the small-scale nature of the research, there was a narrowness in the types of disability covered in the experiences explored.

The benefits of the co-productive approach were in particular the experiences of working in collaboration as a group, immersed in the activity, sharing different perspectives and finding common ground. The group culture that developed, created an openness to new information and knowledge and the sharing of feelings and experiences.

The following feedback has been received from the Expert Researchers:

> For me, it felt that the project was beneficial, it showed what was missing in terms of access in Ipswich for people with a range of disabilities. The research carried out by the participants has enabled people to understand the struggles that are faced daily and how these are overcome. I truly enjoyed working on the project as it gave me the opportunity to take a peek inside the lives of other disabled people. Being a wheelchair user myself, I had the chance to see how they coped with certain issues and then related it to my life in a way, how could i improve things? However, I have not seen many changes throughout my local area and town, parking on pavements, overgrown hedges and so on but it just means we need to fight more for the simple things in life.
>
> It was good to meet other disabled people and hear the difficulties they encounter both with similar problems and with different difficulties.

> The whole exercise made me feel validated, like it was okay to point things out because it wasn't just me that was affected and i wasn't just a moaning Minnie!
>
> I would say that being part of the project gave me confidence in going out of the house again. It made me feel part of the community and it gave me a voice.

Dissemination

So far dissemination has taken several forms. Firstly we organised a series of exhibitions. The initial dissemination event was a half-day exhibition held at the University in Ipswich in order to publicise the findings from this "pilot" phase of the project, which draws on the experiences of disabled people living in the Ipswich area. The photos taken by the co-researchers prior to their interviews were used as a display to highlight both positive and negative experiences – though the emphasis was much more towards the barriers that the co-researchers reported as a significant part of their experiences in going about their daily lives. The photos were organised into the themes identified in the data analysis. A podcast was produced for this exhibition by the project team and the expert researchers, to provide a means of sharing the information about the project with those who are visually impaired.

The exhibition was situated in the ground floor foyer of the University, which allowed people passing through – students, university staff, the general public as well as invited guests to view the photo exhibits. This was done to reach as wide an audience as possible and to raise people's awareness of the issues for disabled people. The same exhibition was also taken to a local library and to the local authority headquarters, supported by a report for the local authority and for the Coalition.

Impact and potential

Findings from this small-scale pilot research project undertaken with disabled people living in the pilot area of Ipswich, Suffolk have been well publicised and received. Now the project intends to extend out across the rest of the county, to maintain the momentum and maximise the benefit of involving trained expert researchers.

It is acknowledged that the majority of the current expert researchers and co-researcher cohort represent the physically disabled community. To address this future recruitment of researchers and participants will include a wider range of disabilities, but if this is not possible, we will engage with relevant local societies and organisations to supplement research findings to ensure the widest range of voices can be heard. However, it is clear that despite the existence of disability legislation, access to amenities and facilities such as shops, transport etc. that enable people to participate in everyday life, remains patchy at best and are still problematic for disabled people. Specific examples have been highlighted throughout this publication, suggesting that progress to comply with disability legislation is slow. To address this issue SCODP have actively engaged with architects, planners and providers of services in Suffolk at the design stage to ensure future developments meet the requirements of all citizens. e.g. SCODP's involvement in The Hold (a public records office) Thetford Forest Visitor Centre and with EDF (an electricity supply company) at Sizewell electricity power plant.

It would be beneficial to investigate the work done in Chester, which has very recently won the European Access City Award for 2017. Forty-three cities across twenty-one EU countries entered for the award. Chester has recognised the importance of improving access for disabled people across its tourist sites and retail, leisure and hospitality amenities, and supporting infrastructure such as accessible toilets, tactile paving, taxi and bus accessibility and the use of accessibility angels, who support individuals accessing the city centre on a one-to-one basis. The city council has endeavoured to design in disability access from the beginning with new developments and make improvements to old ones – e.g. spending £0.5 m per year since 2009 to make most of the city wall accessible to disabled people. There is an access group working within the council, which engages with disabled people to learn about barriers and it is not only the public sector, but also Chester's private enterprises are involved in accessibility initiatives.

> The European Jury particularly appreciated the facilities and measures targeting the most severely disabled visitors. Chester stands out not only for its impressive steps undertaken so far, but also for its long-term approach and ambitious plans for the future (European Commission, 2017).

Conclusion

Many of the findings from this collaborative research project resonate with a publication from the Equality and Human Rights Commission entitled, *Being Disabled in Britain: a Journey less Equal* – a review of disability inequality in Britain, in a report which concentrates on quantitative data, though several of the themes examined corroborate the findings of the qualitative pilot research project undertaken with disabled people living in Ipswich, Suffolk, with depressing conclusions in the face of the existence of disability legislation in the UK created to eradicate and prevent this inequality. Lending weight to the findings from the research conducted in Ipswich, the Equality and Human Rights Commission Report powerfully states that:

> 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, such as being able to access transport, appropriate health services and housing, or benefit from education and employment (Equality and Human Rights Commission, 2017: 7).

However, not all our research focused on the negative aspects of living with a disability in Suffolk. The findings revealed that there are pockets of experience where physical impairment has been thought about when providing services or physical amenities and resources in the community. Positively, the impact of the dissemination of the research findings has produced a greater involvement of the Coalition in planning for community resources in the local area, with the "expert researchers" acting as consultants for new planning initiatives, which suggests that those with the means to effect change have taken note of the serious impact that discrimination has on individuals in the community with specific needs.

The increase in confidence gained by the expert researchers and their increased visibility has been a significant "additional benefit" in several ways. Some researchers have decided to apply for jobs and have used their research experience on their application forms. The group "identity" which emerged from the research strengthened everyone, in that all those immersed in the research had a greater awareness of the world around them and began to identify with not just personal issues but with a sense of a common identity and purpose, and the power of the group to demand change. Co-construction for social change in partnership with the researchers/services users should not be just about the research itself, but, as identified earlier, about the outcomes that are created as a result of it. There is a direct relationship with the methodology – when you actively share power, the benefits of this way of working flow from it.

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