



# The Researched Opinions on Research: visually impaired people and visual impairment research

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**ABSTRACT** *In this paper, we describe our research review, commissioned by 'the Gift of Thomas Pocklington', into the opinions of visually impaired people on visual impairment research. We interviewed 37 visually impaired people across Central Region, Scotland. Our findings suggest areas of need for visual impairment research, both concerning what is researched and how it is researched. We make recommendations for future research addressing both resource and methodological issues. We suggest increasing resources for recruiting participants and multimedia dissemination (e.g. audio tape, Braille, Moon). Methods may need to be refined to address difficulties in recruiting participants, and to capture the diversity of strengths and needs of visually impaired people. We make three core recommendations that identify the need for research to: respect people's individuality; be practical and action orientated, and contribute to an empowering and emancipatory research agenda. We conclude by reflecting on our role as community psychologists through examining the ideological position we adopted in this study.*

## **Introduction**

In mid-1999 we were one of several research projects commissioned by the Gift of Thomas Pocklington (a UK charitable trust that funds research into and provides services for visually impaired people). The organisation's trustees were engaged in a strategic review of their funding practices and sought to gauge funding priorities from the findings of a number of commissioned projects. We secured 3 months funding for our study, which was the sole project to explore the research opinions of visually a impaired people as part of their strategic review. In reporting our study and our findings, we set our task in the context of the wider concerns of disability studies.

Disability research has been criticised for not contributing directly enough in the emancipation of disabled people from oppressive social practices (Davis, 2000).

This has opened important debates on the social and political meaning of disability research sign-posted by several significant texts (Hunt, 1981; Hahn, 1993; Barnes, 1996; Barnes & Mercer, 1997) that have disrupted the hegemony of traditionalist and so-called apolitical value-neutral social scientific enquiry. Increasingly, social science researchers are adapting their ontological, epistemological and methodological concerns to address the socio-political realities faced by disabled people—a reality of acute marginalisation, discrimination and stigmatisation. This reflects trends in the social sciences for research to be grounded more in the political concerns of the field than the academic concerns of researchers. ‘A first requirement of social research ... is fidelity to the phenomena under study, not to any particular set of methodological principles, however strongly supported by philosophical arguments’ (Hammersley & Atkinson, 1983, p. 7). Many areas of disability research are becoming overtly politicised. Epistemological issues remain important, but these are now more explicitly joined by the morals and values that provide a driving force behind disability research. At the coalface, disability researchers are increasingly recognising the expertise of disabled people on disability issues (Zarb 1992), and are becoming more critical of practices that exclude the participation of disabled people in the design, management and evaluation of disability research (Minkes *et al.*, 1995; McConkey, 1998).

The social model of disability has heralded an empowering, emancipatory research agenda with calls for an overhaul of traditional research methods (Duckett & Fryer, 1998; Moore *et al.*, 1998) and relationships (Barnes, 1992; Oliver, 1992; March *et al.*, 1997). The social model defines disability as ‘the disadvantage or restriction of activities caused by contemporary social organisation which takes little or no account of people with physical impairment and thus excludes them from participating in the mainstream of social activities’ [Union of the Physically Impaired Against Segregation (UPIAS), 1976, p. 4]. As such, it focuses on the social, economic and political barriers that ‘disable’ people who have impairments and contrasts the medical model of disability that equates disablement with impairment alone. In our review of social science literature, we were unable to find examples of research informed by an empowering and emancipatory paradigm involving visually impaired people. Such research is at best unrecognised and at worst considerably underdeveloped. This contrasts quite starkly with research involving disabled people more generally, where the social model and the use of empowering and emancipatory research designs are growing.

Recently, Kitchen (2000) researched the opinions of disabled people on what disability topics should be researched and how such research should be researched. He concluded that there was parity between the opinions of participants in his project with the views promoted by disabled academics, as both called for more extensive use of emancipatory and empowering research strategies. Kitchen’s study was published shortly after we completed our study and later we reflect on what our study adds to Kitchen’s findings.

### **Community Psychology**

As psychologists we belong to a professional discipline that has historically con-

tributed to the oppression of minority groups in society. Disabled people, women, ethnic minority groups, lesbian women, gay men and low-income groups have all found themselves brutalised by psychological discourse. In particular, we have inherited a rather inauspicious history that has condoned the incarceration, sterilisation and medicalisation of disabled people. This has been achieved through, among other tactics, the construction and use of tools such as Intelligence Quotient (IQ) tests and the mental health Diagnostic Statistical Manual (DSM). Both are riddled with disablist, racist, sexist, homophobic and middle-class ideologies (see Albee, 1988, 1996; Albee & Perry, 1998). Much of psychology remains harmful, both in theory and practice, to disabled people. Psychology continues to be engaged in the widespread reification of intrinsically social and economic problems within communities as individual medical aberrations requiring clinical and medical treatment, rather than socio-political intervention (see recent debates on the treatment of Attention Deficit Hyperactivity Disorder, e.g. Lloyd & Norris, 1999; Baldwin, 2000). Psychology continues to be concerned with fixing people at the neglect of fixing places (Lukes, 1973).

However, as *community* psychologists we have joined the increasing numbers of people who position themselves against oppressive practices in psychology. ‘Community’ is used less as a taxonomical tool signifying the area of psychological enquiry we study, but more a signifier that positions us ethically and politically towards psychology in particular and the social sciences in general (Engelberg, 1981; Duckett, 1998). ‘Community’ tempers the title of psychologist with particular ideological and ethical concerns. These include the way community psychology:

- positions itself critically against all forms of victim-blaming ideology (Ryan, 1971);
- seeks to work in ways that are empowering for members of socially, economically and politically disempowered, disadvantaged and marginalised groups (Rappaport, 1981);
- avoids reifying intra- and inter-disciplinary boundaries between professional, para-professional and non-professional groups (Sarason, 1976);
- seeks to identify and remove structural, socio-economic inequalities (Reiff, 1975; Maton, 2000).

Community psychology formed the value-base that guided how we approached and worked with participants, and how we interpreted and reported our findings.

## Recruitment

We used opportunistic and snowball sampling (re: Coyne, 1997) to generate our sample of participants, working with three visual impairment organisations (a local RNIB organisation, a visual impairment organisation in Edinburgh and a regional Society for the Blind). We asked each organisation to send a recruitment package (consisting of information on the research project, a brief literature review of visual impairment research and a letter of invitation—all printed in large text) to potential

TABLE I. Age of participants

Age (years)	Number of participants
30–45	11
45–60	13
60–75	11
75 +	2
Total	37

research participants on our behalf. These organisations sent the recruitment packs to a broad range of visually impaired people reflecting diversity of geographic location, age and gender. We were aware of the suggestion that younger visually impaired people may have views very different from visually impaired people older than 75 years (RNIB, 1991). With the likelihood that we would recruit larger numbers of older participants, given the higher numbers of older people in the visually impaired population, we actively sought to recruit younger visually impaired people. (We have recently completed a study into the opinions on visual impairment research of people over the age of 75 years; Morton & Duckett, 2000.) Combined, these organisations sent recruitment packs to 110 clients. Sixty-six potential participants did not reply and seven replied stating they did not wish to be involved in the research. The confidentiality of the recruitment process meant we were unable to analyse the characteristics of non-respondents and those who declined our invitation.

## Participants

We interviewed a diverse range of people, varying in level of impairment, geographical location and age. Our sample consisted of 37 participants from an area in Central Scotland within the triangle roughly bounded by Stirling, Glasgow and Edinburgh, though this included one participant in Aberdeenshire and one in the Scottish Borders. Participants lived in urban areas (18 participants), outlying housing schemes with multiple deprivation (four participants), and suburban and rural areas (15 participants). Participants ranged in age from their early thirties to late seventies (see Table I). Twenty-two participants were female. We were unsuccessful at including ethnic diversity in our sample, which is partly due to the low level of ethnic diversity in Central Scotland compared to Metropolitan areas in the UK.

Participants included both those registered as partially sighted and those registered as blind. Two participants had complete sight loss. Impairments included glaucoma, macular disease, retinal detachment and Leber's Atrophy. We also talked with participants with multiple impairments. One participant had partial paralysis, one participant had a learning difficulty and one participant had epilepsy. We did not ask participants to disclose the nature of their visual impairment or any additional impairment, as this was not in accord with the Social Model of disability

we adopted (i.e. we sought to focus on disabling environments, rather than an individual's impairment). Most participants, however, chose to disclose this information to us.

## Methods

We conducted 30 individual interviews, three at a university office, one at a participant's place of work and the rest at participants' homes (locations were decided by participants). We also conducted seven phone interviews towards the end of the fieldwork period to reach our required sample size within the time scale of the project (recruiting participants took longer than we had anticipated and we discuss this later).

We used non-standardised interviewing techniques (Denzin, 1970), adopting a suspended structure interviewing format (Duckett, 1998) that offered each participant opportunities to direct the course of the interview. This permitted participants to approach the topic in her/his own way. We sought to develop egalitarian research relationships between the interviewer (PD) and participants. We therefore aligned our methodology to a person-centred approach (Levant & Shlien, 1984), an approach we have used previously when seeking to establish egalitarian research roles with participants with learning difficulties (Duckett & Fryer, 1998). This entailed:

1. Holding an unconditional positive regard for each research participant—adopting a non-judgmental acceptance of each participant's experiences, opinions and feelings.
2. Reinterpreting research roles so that the locus of expertise shifted from the researcher to the participant—participants became the experts and the researcher became the novice.
3. Viewing participants as research collaborators, rather than 'subjects' of investigation.
4. Avoiding acts of deception and freely eliciting our own feelings and experiences if participants asked for them.

Through this approach we emphasised developing a relationship of trust, openness and informality with each participant. In political terms, we sought a democratic relationship with each participant. We have subjected this approach to rigorous empirical analysis, which suggests our methods are successful in redressing power imbalances between researchers and participants in social science research (Duckett *et al.*, 2000).

In case participants felt they did not know enough about visual impairment research, we sent our own review of visual impairment research and a summary of the medical and social models of disability as a stimulus for discussion. We designed the review to be accessible to a non-academic audience. This review is available in our final research report (Duckett & Pratt, 1999), which was also written for a non-academic audience. We recognised that participants could find their own way to talk about research issues, but that some would prefer to have a

more concrete stimulus for discussion. This also secured a greater parity between participants' and researchers' knowledge of the existing state of play of visual impairment research and of the key theoretical debates in disability studies. Participants welcomed this additional information. All participants referred to the summary during our interviews, although none used the structure of the summary to structure their interview: all found their own ways to structure their discussion of the research topic.

With each participant's permission we tape-recorded our individual and phone interviews. We did our analysis directly from tape, using a process of inductive inquiry to allow themes to emerge from the data. We organised these emergent themes through applying cognitive mapping procedures—'a method of modelling persons' beliefs in diagrammatic form ... developed in the context of action research' (Jones, 1985, pp. 159–60). In our findings section, we summarise this data through focusing first on what participants wanted researched and then on how participants wanted this research done. We sent all our findings to participants prior to writing the report as a form of member check. All participants contacted were content that our findings represented their opinions and experiences.

### **Summary of Findings**

Participants wanted the following topics researched:

- access to the environment;
- access to information (including socio-medical issues involved during diagnosis and treatment);
- attitudes (stigma and its impact on education and employment opportunities);
- civil rights (problems of collective action and relationship to the disability movement, organisational and political issues including user roles in visual impairment organisations, allocation of resources);
- support (social and financial).

Participants suggested the following areas of concern for *how* research should be conducted:

- recruitment of participants;
- accessibility of research findings;
- power dynamics of research relationships;
- recognising the individuality of participants;
- practicality and utility of research for visually impaired people.

### *What Should be Researched*

Participants identified topics they felt warranted further research attention. We have classified these into separate sections, though there are considerable overlaps across

some of them. We have used pseudonyms, rather than participants' real names to ensure anonymity.

### *Access to the Environment*

'It's getting about that's the problem. You can't read street names 'cause some idiot in the council thought it would be cool to put the signs half way up the sides of buildings ... You can't see the number of the buses and by the time you do the wee bugger [bus driver] has taken off up the road without you. (Alex, individual interview)

Participants described their own difficulties in accessing public areas and drew our attention to the need for research into the physical barriers many visually impaired people encounter. Because of the wide variation of visually impaired people's aspirations, abilities and needs, participants described how aspects of the environment that enable some can disable others. One participant who, as well as having a visual impairment, had a mobility impairment found tactile pavements (designed to alert visually impaired pedestrians of a road crossing) particularly problematic:

The council put in these paving stones to help people like me know when they're next to a pedestrian crossing. Now that is all well and good, ken, but it actually doesn't help me because I find it too difficult to walk on because the pain just jars right up my leg, it is the same as how I can't walk on cobbled streets. (Joyce, individual interview)

Access arrangements designed for disabled people whose impairment was not visual could also become barriers for visually impaired people. One example was of automatic doors:

You don't see the thing [automatic door] coming for you, by the time you get closer enough to see it's a door the damned thing is already taking a swing for you. (John, individual interview)

Participants wanted research to make the public and town planners more aware of the conflicting interests within the disabled population. Meeting the needs of some individuals may be at the cost of other individuals due to the diversity of people's impairments, strengths and needs. Participants showed us how this diversity needs to be carefully considered in planning processes. We believe this holds equally for disability researchers as it does for town planners and we discuss this later under 'making research different'.

Mobility and transport issues were important to participants. The lack of adequate transport was described as resulting in many visually impaired people living in isolation. Transport was felt to be the key to visually impaired people fulfilling their potential and playing an active role in society.

### *Access to Information*

Participants discussed the issue of how and if information was disseminated to

visually impaired people—both general information (i.e. local news, information on services and consumer products) and more specialist information (i.e. that produced by research and medical practice):

Have a see at what these doctors do with all their information. They certainly don't give it to me. Go and ask other people like me what they have been told and what they haven't. I reckon not many people have been told much about anything that's wrong with them. (Jim, individual interview)

Participants highlighted the importance of finding effective ways of facilitating the exchange of practical knowledge between visually impaired people. The 'practical solutions' participants referred to came from visually impaired people's specific trial and error experiences of daily living, as well as more generic knowledge of services and facilities available to visually impaired people in the local community. Participants described various 'tricks of the trade' that made life easier which they had wished had been passed on to them earlier:

If you try to put the toothpaste on the toothbrush you will get into a right mess. Then I found that if you put the toothpaste straight in your mouth rather than on the toothbrush then it was problem solved. I wished someone had told me that earlier ... it would have saved me a lot of laundry and a lot of toothpaste. (Jerry, individual interview)

The 'talking book' was a resource valued by many participants, particularly one participant we interviewed who had a learning difficulty. During our interview he proudly showed us his tape machine. Some participants were concerned about the planned change from audio tapes to a CD ROM format and wanted research into the implications, both for service providers and users, of these anticipated changes:

I don't think they have really thought it through. Do they know that everyone is alright with the new machines, or has everyone got access to computers and things? (Diane, individual interview)

### *Diagnosis and Treatment*

Participants felt they were denied access to medical information during the diagnosis and treatment of their visual impairment. Participants were concerned to make the process of diagnosis and treatment much more open and transparent:

I just didn't ken what was going on, didn't understand what they was talking about, what they was testing and what it all meant. (David, individual interview)

Participants were also concerned at how visually impaired people were classified as either 'blind' or 'partially sighted', feeling the public were more accepting and understanding of the concept of blindness than of partial sight and felt the meaning of these classifications needed considerable unpacking:

When you tell them that you can see things out the corner of your eye they says back to you that they thought you were blind. They don't get it that you can be blind but still see bits and pieces. (Neil, individual interview)

### *Attitudes and Stigma*

Stigma towards visually impaired people was a strong concern for participants. One participant felt visually impaired people were either seen as too young to have independence or too old to contribute to society:

It's like the cradle to the grave, except we are made to miss out the bit in the middle. (Ann, individual interview)

As well as desiring research that would map out the pervasiveness of such stigma, participants wanted research to change attitudes.

Participants felt visual impairment was the impairment the public most feared getting themselves, attracted the biggest 'sympathy vote', and was associated with the greatest perceived dependency.

You get people grabbing you by the arm and trying to drag you across the road if they see you waiting at the kerb. I tell them to 'Get arfff'. They just think, oh look, there's a cripp [abr. cripple] we must go and help the poor wee soul. (Ann, individual interview)

Some participants were concerned at how visually impaired people were socialised into a sighted world and the lack of visual impairment role models to serve as an alternative to this socialisation process.

You can tell folk who have been to the Blind school cause they have been taught to act like sighted people ... The school just tries to make them look like sighted people. They haven't been given blind role models, they've only got sighted people, telling them how they should act. (Ann, individual interview)

This was described as preventing visually impaired people from constructing their own social identity. Participants wanted to know more about these socialising processes.

### *Education and Employment*

Participants were particularly concerned of the role of stigma in the provision of education and employment opportunities for visually impaired people.

The biggest thing is getting a job, and next to that I suppose is getting an education so that you can get a job. There is so much that is going against you if you are registered blind. Employers don't want to know and you are sent off to special schools which aren't a lot of good, you are just kept out of the mainstream, don't really stand a chance. (Keith, individual interview)

Participants wanted a better understanding of discriminatory processes in the recruitment, retention and promotion of visually impaired employees and how having a visual impairment identity effected access to education. Participants wanted more work done on improving employers' attitudes towards and increase the educational and vocational opportunities for visually impaired people.

### *Civil Rights*

Participants wanted research to approach visual impairment from a civil rights perspective, politicising many of the research issues they identified. There were two strands to this—political action and resource allocation.

People wanted to know how visually impaired people could best participate in collective action, to engage in lobbying local and national government, and to become part of the wider disability movement. Participants further felt research should focus on the level of involvement visually impaired people have in the organisations that deliver services to them. Collective action was seen as problematic for visually impaired people and participants felt research should explore what impedes visually impaired people from joining visual impairment groups or using peer support (from other visually impaired people) or, as one participant put it, 'getting people out of the woodwork'. We will discuss this in more detail when we describe participants' views on how research should be conducted.

Participants also focused on how resources were distributed through service provision, focusing in particular on the allocation of information technology and visual aids among the visually impaired population. This also addressed the issue of who was in control of the design and distribution of new technology. One participant clarified the distinction between low and high tech solutions when, after describing her preference for using a finger, rather than a electronic sensor to tell how much liquid was in a cup, she explained 'the battery doesn't wear out in your finger'.

### *Support*

*Social support.* Participants were interested in the support that a visually impaired person receives from their family and friends, and the way that support can aid a person's adaptation to their environment. This topic also included interest in the strategies visually impaired people use to turn down unwanted support from well-intentioned others.

It's difficult telling people that you don't need their help without hurting their feelings. There should be some guidance for folk, you know, the best way to handle situations like that. (June, individual interview)

Participants felt it important that research makes clear the different support needs of visually impaired people who live alone, and those who live with partners and family.

Participants also felt that research could help to make the public aware of just

how much effort visually impaired people have to put into doing everyday tasks, such as shopping and travelling and how valuable good quality support is (e.g. assistants in shops, disability aware bus drivers, etc.). Participants felt research could draw out the strengths people have which would contribute a more positive image of visual impairment to counterbalance the over-emphasis on the negative effects of visual impairment that dominates public thinking.

*Financial support.* Participants were concerned about the lack of attention paid to the poverty many visually impaired people face and the difficulties many experience in accessing their disability benefit entitlements. Participants felt research should focus both on the visually impaired individual's experiences of claiming welfare benefits and suggest improvements to the management of the benefits system, making it more accessible to visually impaired claimants.

If they could spend more time on ways of making [disability benefit] forms and leaflets more easy to understand, that would be time well spent.  
(David, phone interview)

## **How Research Should be Conducted**

These findings concern how research should be done and, as such, focus on concerns participants had about the processes involved in conducting research.

### *Getting People Out of the 'Woodwork'*

Participants believed large numbers of visually impaired people remain hidden from services. As mentioned earlier, this was described by one participant as visually impaired people 'staying in the woodwork'—not coming out and making themselves heard, and making their aspirations and needs known. This may have been a reason for the slow response rate during recruitment of participants for this project—visually impaired participants may have been reluctant to speak up on issues related to visual impairment. If so, it would be an issue that needs considering when recruiting participants for visual impairment research.

It may be prudent to seek an 'unrepresentative' sample of visually impaired research participants (participants who are prepared to speak up on visual impairment issues) as a representative sample might include large numbers of people who do not wish to discuss visual impairment issues (re: Beresford, & Campbell, 1994). For example, if the research topic was the barriers in the social environment that disable people with a visual impairment, it may be counterproductive to seek the views of people who would play down the real difficulties they face. However, it seems unsatisfactory not to seek the opinions of people whose views are more often left unheard, as this would be more a part of the problem than the solution. It would be important for researchers to develop strategies that would enable them to access the opinions of 'hidden' visually impaired people. Such matters may need careful thought in research design.

Participants felt that researchers should not assume that visually impaired people would necessarily wish to be involved in visual impairment research. People may not want to be involved in research if that means they have to be identified as visually impaired or means they have to associate with other visually impaired people. This should caution researchers to think carefully about the implications their research activity has on a visually impaired person's identity and the resulting psychological costs that the visually impaired person may incur. From talking with participants it became clear that some visually impaired people found the prospect of associating with other visually impaired people to be unattractive. Participants evoked the image of the 'Blind Club' as a wholly unattractive one. It is interesting to note that of the 30 participants who became involved in individual interviews (not including phone interview participants), not one stated a preference for a group interview (an alternative that was offered to participants). This merits thought about developing empowering research practices. More thought needs to be given to how we create research settings where visually impaired people have the opportunity to share experiences with one another, and find common concerns and strengths.

#### *Making Research More Transparent*

The impenetrability of most visual impairment research (written in an academic and/or a medical language) and its inaccessibility (written in esoteric academic journals) concerned participants. Many felt research should be written in plain English. This was described as of particular importance given the large numbers of visually impaired people who are elderly. Participants felt this section of society was particularly likely to be alienated by turgid, academic prose. One participant suggested there should be a code of practice for research that stipulates research should be written in plain English. Participants further believed the findings of research needed to be made available to visually impaired people. Participants found it ironic that most papers written about visual impairment were only available in a purely visual medium. Participants pointed to the need for careful attention to how researchers disseminate their findings, particularly to how or rather if research was reported to visually impaired people. Participants felt funders of research should ensure projects are adequately resourced to disseminate information on tape and in Braille.

Generally, the over-arching aim of research (the growth of knowledge and understanding) sat incongruent with what participants perceived to be happening—the increasing bewilderment of the many (visually impaired people) and increased understanding of the few (academics and medics).

#### *Power Dynamics of Research Settings*

Issues of disseminating information further generated discussion on the power characteristics of research settings. Some participants' only experience of research was of being assessed and treated for a visual impairment in a clinical setting. In such a setting, the doctor-patient relationship was described as disempowering.

Participants talked of being given only the minimum amount of information sufficient to ensure their compliance with a clinical procedure, but of not being able to question the doctor about the procedure or to tap the more general ‘expertise’ of the clinician. Participants occupied a compliant and passive role, and felt bound by social conventions that made asking questions socially more uncomfortable than answering questions. Participants felt it important that the research relationships that develop between researchers and participants in visual impairment research should not mimic the power dynamics of a doctor–patient relationship. As well as maintaining courtesy towards and the dignity of visually impaired people, participants also wished for research settings to achieve a level of respectful informality that would allow visually impaired people to question researchers and to satisfy their own informational needs. This was a concern in reaction to what was perceived as the subterranean processes inherent in research, processes that were hidden from participants and thus never subject to the participant’s scrutiny.

### *Making Research Different*

This concern developed from the recognition of the multiplicity of needs of visually impaired people. With the high degree of variability among visually impaired people in their level of impairment, and the nature of their strengths, needs and aspirations, participants recognised that a single focus approach would be misplaced. Participants described the need for research that used different ways of asking questions, collaborated with a variety of agencies and was undertaken by a wide range of research organisations. Participants were opposed to being clumped together in large groups of visually impaired people with whom all they shared was owning the same diagnostic label. This is closely related to the earlier theme of ‘access to the environment’, where participants pointed out the diversity of disabled people’s strengths and needs.

### *Practicality and Relevance*

You understand us better but it doesn’t help us. (Lynne, telephone interview)

Participants felt research needed to be practical and relevant to the immediate and everyday needs of visually impaired people. The focus was less on exploring the intricacies and complexities of a research topic (a theme many participants associated with traditional forms of research). Rather, the focus was on the need to look at the more apparent and immediate problems visually impaired people encounter, and to search for practical, inexpensive and simple solutions, or as one participant expressed it:

We don’t just need people to tell us why it rains, we also need people to invent things like umbrellas. (Jane, individual interview)

There was a considerable sense of urgency expressed by many participants with

research that did not produce immediate, beneficial results for visually impaired people. As such, there was much support for Action Research strategies—research that seeks change as part of the research process. Increasing the practicality and relevance of research through Action Research may help in encouraging people ‘out of the woodwork’ and increase the involvement of people with visual impairments into research. Participants also wanted more funding for research that had a political edge and for funders to encourage research that provided support for effective political lobbying on visual impairment issues.

### *We Know Best*

You have to live with it to fully know what it means. (John, individual interview)

Participants emphasised the vast pool of expertise owned by visually impaired people and that research needed to learn from visually impaired people: to tap into that existing expertise, rather than to try and generate new knowledge. In particular, the expertise in independent living skills that visually impaired people gain by just ‘muddling through’ was felt of value to people who had become recently visually impaired. There was a feeling that the wheel was being constantly reinvented by research into visual impairment. Participants felt researchers would make a far greater contribution to the field if they helped to more widely distribute the knowledge that was already there, rather than seek to create new understanding. This whole issue centred on the flow of information. Unlike the need we describe earlier for the information to flow from researchers to disabled people through more effective dissemination strategies, here the information needed to come from disabled people to researchers. Participants felt that visually impaired people should be consulted more thoroughly on research design and practice, and have more control over research activities.

### **Research Reflections**

The common thread in all participants’ input to this project was a focus on human rights issues, whether it was through focusing on access, attitudinal, economic or informational issues. As such, our research findings are similar to that reported by Kitchen (2000) and replicates the opinions of disabled people more generally identified by the growing disability movement where human rights has become a prominent concern. Our conversations with participants may have taken this human rights focus through our presenting participants in the first instance with our views about the social model. Participants readily adopted this model as significant and relevant. We feel it possible that our approach opened up the room for participants to talk about human rights issues. This may or may not have been the case had we adopted a medical model perspective. However, it is also likely that we spoke with the more active, outspoken and political clients of the visual impairment organisations we contracted and the findings of this project might reflect that.

The nature of the issues participants described draw us to make suggestions for future visual impairment research. We believe a number of issues should be considered. The first relates to the lessons we learnt from this review. This involves reflecting on the resource implications of and participant recruitment strategies for undertaking research with visually impaired people. The second relates back to the general concerns expressed by participants. These issues point to the need for visual impairment research to:

- respect people's individuality;
- have a practical focus and be action orientated;
- to contribute to furthering an empowering and emancipatory research agenda.

### *Resource Implications and Recruitment Strategies*

We conclude that research with visually impaired people needs to be adequately resourced to make use of alternative formats to disseminate information. In this study, participants had experience of and, indeed, were expectant of difficulties and delays in receiving information in alternative formats. We feel that visual impairment research should seek to disconfirm participant's expectations by being adequately resourced with both time and money to use multimedia forms of disseminating information.

We also conclude that research involving visually impaired people needs to consider more innovative ways of recruiting participants. We feel that the whole process of recruiting participants needs rethinking both in terms of the strategies involved and the resources that may need to be invested. For example, it might be prudent to use a more personal form of initial contact with potential participants who have a visual impairment. For example, rather than mailing invitations out, the researcher could seek first to access the potential participant's social network and find someone who could approach the person, in person, on the researcher's behalf. This entails additional confidentiality and ethical issues that already plague the practice of researchers working with people with learning difficulties and people who have dementia. In both cases, researchers regularly use 'proxies' to obtain access, as well as informed consent. Using proxies in the consent process can address the need to provide support for some people in becoming involved in research. This support, whilst more ethically complicated, can work to increase safety and decrease risks for people considering being involved in research (Pratt & Wilkinson, 2001). This could also mean the recruiting stage becomes considerably more time consuming. It could further mean that the researcher is transferring onto others the ethical dilemmas and responsibilities of recruiting participants and, in this respect, there is a considerable risk of such recruitment strategies becoming exploitative. However, done with care, this might avoid the problems of using inappropriate means of first contact with participants (i.e. printed text/audio tapes/Braille, etc.), might increase the recruitment of participants who are hidden from visual impairment services and reduce the

risk of researchers imposing unwanted social identities upon participants (i.e. 'visually impaired').

With the possibility that large numbers of visually impaired people are unknown to services and/or do not wish to self-identify as visually impaired, the numbers that can be expected to be involved in a succession of research studies may be small. Also, with people varying widely in their strengths, aspirations, needs, and levels and types of impairment, the differences between individuals in the visually impaired population is likely to be proportionately larger than in the general population (Miller, 1997). This has implications for research design. For example, this might suggest that more in-depth case study approaches, designed to understand the perspectives of a small number of visually impaired people who have diverse backgrounds and interests, may be more appropriate than large scale surveys.

There were certain groups of visually impaired people that our study failed to access. We originally sought to meet people from different ethnic groups, but due to difficulties in recruiting participants and general issues of the representation of visually impaired people, which we discussed earlier, we were unsuccessful in this. We would urge future research activity into visual impairment to access the views of visually impaired people from ethnic minority groups. We feel this is an important element that was missing from our project. We also failed to meet participants who had both sight and hearing loss. We therefore feel that a further priority in research activity should be to see the views of people with such a dual impairment. Doing so, however, will have resource implications above and beyond those that we have already identified. A considerable amount of time would be required to fully access the views of people who have total sight and hearing loss, as communication can often take longer. If deaf-blind interpreters were not employed, researchers would have particular training needs before undertaking such a research review, for example training in finger spelling.

#### *General Concerns Identified by Participants*

The recommendations we make above concerning small sample sizes including a diverse range of individuals was suggested in a different way by participants. Here, the concern was that research should capture the individuality of visually impaired people, and to recognise that visually impaired people are first and foremost people, who are as idiosyncratic as anyone else. Participants felt the practice of labelling and grouping people together to discover how much alike visually impaired people are did considerable harm to visually impaired people's social identities. Based on these concerns, we would recommend an eclectic approach to research on visual impairment that focuses on multiple topics (such as those suggested in our findings), multiple methods and from multiple perspectives to discover whom people are rather than whom people are like.

Participants felt quite strongly that visual impairment research should have practical and immediate benefits for visually impaired people. This was highlighted in participants' focus on sharing with newly visually impaired people the simple,

low-tech solutions to the everyday difficulties that confront visually impaired people. Participants felt dissatisfied with research activity that promised much, but appeared to deliver little. The assurance that research is being done for the common good and that positive change, if any, may happen after the research has been completed was seen as too little, too late. The need is to attend not just to the final outputs of a research project, but the through-puts, i.e. not waiting until the research has been completed for positive change to be realised, but to seek positive change through the very process of doing the research.

For some participants, their ambitions were greater than this. Some felt that the action element of research into visual impairment should also take on a political edge to confront issues of how to facilitate structural changes in society that will have benefits for visually impaired people. This is clear in the needs participants expressed for research that improved access to public spaces, and that changed the attitudes of the public, service providers and employers. In light of this, we would suggest that objective, value-free, depoliticised research activity may be inappropriate and ineffective in meeting the concerns participants expressed on these issues. However, participants also expressed concern about the difficulties of seeking to engage with visually impaired people in collective action. This suggests that sensitivity and creativity needs to be exercised when including political dimensions in visual impairment research.

From talking with participants it was also clear to us the need for researchers to redress power inequalities in the relationships that develop between researchers and visually impaired people in the research process. This was suggested tangentially through participants' concerns of the lack of information that was flowing from researchers to visually impaired people compared to that flowing from visually impaired people to researchers. It was suggested more directly by people describing the passive roles they occupied in clinical research settings. Based on this, we would encourage research that seeks not just to include visually impaired people into research activity, but ensure that the research roles visually impaired people occupy are sufficiently empowering.

### **Authors' Final Reflection**

We believe the ideological position (e.g. medical model/social model) upon which any research review is based should be made explicit. We believe it is important that funders recognise that just because an ideological position is not stated in research this does not mean it is not there. Our own focus on the social model and community psychological practice led to insights conveyed by participants that may not have come about if an alternative perspective were adopted, or may not have been as comprehensible had we not made our ideological position explicit. Our findings echo the concerns in a growing number of publications in disability studies, and this may have much to do with the synergy between our community psychological approach and the social model of disability. Though the human rights angle we identified through our findings is informed by the particular ideological position we took at the beginning of the project, we feel that participants clearly articulated the

need for such research. However, such a singular focus may be problematic (re: Young & Quibell, 2000). It also begs the question that had participants in this project wanted less rather than more empowering research practices, would we have supported their views so vociferously? We must confess no. We have rejected aspirations for value-free, politically neutral forms of research engagement and have clearly articulated the values behind our research. Rather than being neutral observers who occupy the role of recording and disseminating the views of participants, we flavour the observations we make and the forms of dissemination we chose with the ideological position we adopt. More so, we have an obligation to foster those political values in others (Berkowitz, 2000). We have both worked extensively with disempowered groups and through such experiences we remain ethically and morally committed to a community psychological way of working (re: Cowen, 1977; Trickett, 1984; Kelly, 1986). We remain unapologetic about our political engagement in the field and candid about the way we engage with our research.

As a piece of empowering research, this review has both strengths and weaknesses. It was a review commissioned by a disability service provider/research funder. The report had a positive impact upon the funding priorities of an organisation that had previously prioritised bio-medical over socio-political research. Since submitting our report, the funding organisation has shown further interest in developing research projects informed by a social model perspective and an emancipatory research agenda. Our project also engaged us in empowering, research practices with disabled participants. As well as accessing the views of disabled people directly, we carved open spaces for participants to occupy more egalitarian research roles with us.

Seen in isolation, however, this project falls short of those very aspirations for visual impairment research voiced by our research participants—of engaging in research that has an immediate practical and action orientation. Given the small time scale of the project (3 months) and limited budget this is perhaps unsurprising. As community psychologists we seek to engage in social action on multiple levels. In this study, we had the opportunity to engage in practical action on two levels. First, we could employ a methodology and a value orientation that would permit disabled research participants to occupy empowered roles in the research process. Secondly, we engaged in action at an organisational level through influencing the funding practices of a visual impairment organisation (the Gift of Thomas Pocklington). In the present political climate it may be easier to make research funding recommendations than to get such emancipatory research funded. Research funders in the UK, such as the Joseph Rowntree Foundation and the Economic and Social Research Council, are promoting more inclusive, empowering research practices with marginalised groups. However, it is still the case that research projects that are ontologically, epistemologically and methodologically grounded in emancipatory goals may create friction with a social science that continues to be dominated by a positivist, conservative scientific paradigm. This has been the experience of many working within community psychology and community activism who find it difficult securing funding for projects that have the potential to unsettle the status quo (Berkowitz, 2000). Therefore, although the organisational level of our action remains for many

participants quite distal, we are still convinced that it is an important area for action: to target research funding organisations to change their funding priorities.

We do not say this to encourage complacency in the meantime. Indeed, this contextualising of our project within such temporal, financial and political boundaries does not satisfy us that we engaged in action as fully as we could or satiated our need to engage in positive action as fully as we would want. We remain unsatisfied that the project could not engage in action at levels additional to those we operated at. We would add that research should simultaneously work to secure more tangible and immediate benefits for disabled people. The question, we feel, should not be about engaging in action at the right level, but about engaging in action on the right number of levels.

To conclude, we feel researchers should consider the ideological position they adopt, as this will affect how their research findings are reported. In light of our own ideological position and the feelings of participants in this study, we believe future research should adhere to the following principles:

- people need to be placed at the centre of both developing and conducting research;
- research needs to be practical and relevant;
- the over-arching aim of research should be to further the empowerment and inclusion of visually impaired people.

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