

Building Bridges: disability and old age



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Summary

The purpose of this short pilot project was to make an initial examination of the representation of claims by older people's groups, from a critical disability studies perspective. We hoped to provide an initial base from which to develop a theoretical frame for thinking more clearly about policy making and political activity in relation to disability and old age, and to explore the potential for tactical or strategic alliance between advocates of disability rights and older people's rights.

Our concern with these issues arose from an apparent paradox in disability politics, policy and research. While the majority of disabled people in Europe are also older people, older people's interests have been under-represented within both the academic literature of disability studies and in disability policy making (which have tended to focus on the needs of younger adults and to a lesser extent children). Conversely, while there has been a great deal of recent academic and policy interest in issues of aging (for example, through the ESRC *Older People* Programme) there is little evidence of an active interface with disability issues and theory. With this in mind, the project sought to identify areas of common ground in contemporary thinking and policy making on disability and ageing, and to provide an initial exploration of the potential for increased political collaboration between the two social movements concerned.

The research involved a combination of (a) academic and policy review in a national context and (b) the collection of data from local organisations representing or responding to the claims of older people. The proposal was developed in consultation with older people's organisations (both nationally and locally) and these provided the focus for the research. The review of policy making focused on the national context, and specifically on developments under New Labour. The emphasis here was to examine the membership of policy communities and the representation of disability issues within policy debates on ageing. A selective case study approach provided a means to balance the general breadth of coverage with a greater depth of analysis on significant policy debates.

The local data collection was focused on a single local authority area in the North of England. This involved a postal survey of 72 local voluntary sector organisations (57 returns), textual analysis of organisational documentation, and individual key informant interviews with representatives from 21 of these groups. The survey addressed issues of organisational structure and focus, while the interviews were primarily concerned with cultural constructions of older disabled people and their needs. The key informants were self-selected within organisations and the interviews were conducted by a disabled researcher. Given the time constraints of a six-month project, this mixed methods approach generated a large amount of rich data (both qualitative and quantitative) and provided a useful balance between surveying the broad context and exploring detailed accounts and meanings.

We were able to highlight key areas of contemporary policy debate where the needs and claims of older disabled people were being represented. Within the national context, it was evident that organisations 'of' and 'for' disabled people had an interest in issues affecting older people and that they were sometimes consulted as significant stakeholders within those debates. However, it was also evident that policy forums addressing national ageing issues did not always incorporate informed disability perspectives and that this adversely influenced the way in which older disabled people's needs were constructed and addressed.

The combination of data, from our policy review and from the participation of local organisations representing older people, allowed us to identify a number of key areas in which there may be considerable potential for greater political alliance or tactical collaboration with the disabled people's movement. For example, we were able to provide significant examples of organisational priorities in policy areas of common interest such as: health, housing, transport, incomes, social care, employment, and so on. However, we were also conscious of potential barriers to the successful mobilisation of such political alliances arising from a cultural distancing of old age from disability identities within the movements concerned.

Our emphasis was on the experience and perceptions of local organisations. Here it was evident that local older people's organisations were in contact with substantial numbers of disabled people but that they sometimes struggled to respond adequately to their needs. There was great diversity in the way that organisations viewed older disabled people and in the way that they perceived their role in this context. Constructions of old age and disability tended to emphasise individual physical functioning rather than enabling or disabling environments, often separating the needs of people with significant impairments as 'other'. In this respect there were marked differences of opinion about whether people with age-related impairments might be considered as disabled people or whether they should be included within the generational norms of old age.

Although our initial pilot project did not involve biographical work with older people themselves (unless they were also key informants within organisations) we were able to collect interpretive data from organisations about their perceptions of ageing and identity in relation to disability. In this sense, we were able to confirm anecdotal evidence that older people with impairments are often not seen to be disabled in quite the same way that younger adults often are, and that they may not see themselves in this way either. This finding merits further investigation in a larger scale qualitative study involving older disabled people.

In addition to the identification of policy issues and cultural constructions, we were able to offer an initial analysis of factors influencing the political mobilisation of movements concerned with disability rights and the rights of older people. Our research suggested that a large proportion of local voluntary sector groups had been involved in some kind of campaigning activity on older people's issues, and that amongst this group there was a readiness to become involved in disability related issues. This suggested a clear potential for increased collaborative alliance with disability organisations. However, it was also clear that older people's organisations often lacked the conceptual or linguistic resources to articulate these concerns within a social model of disability, and that this raised some barriers to the possibility of such joint working. Groups that were already politicised in relation to issues of racism/ethnicity or gender equality appeared to be much more open to a similarly politicised view of disability rights.

Our findings suggest that there are many policy issues of common concern to disabled people's organisations and those representing the claims of older disabled people, but that there remain cultural barriers on both sides to the identification of commonality between older and disabled people. There was evidence of the potential benefit of disability equality training with older people's organisations, which might lead to greater collaborative advocacy or tactical alliance between the two movements concerned.

Full report of research activities and results

Background

Approximately 70 per cent of Europe's 30 million disabled people are over 60 years old, yet there is very little research about disability rights from the perspective of older people. There have been some studies about ageing with particular kinds of health conditions, and some theorising that draws parallels between the structural or cultural construction of disability and old age, but little exchange of ideas about the common ground of disability equality and age equality.

There has been an increasing awareness of the world's ageing population, and repeated calls for the rights of older people. The recent International Year of Older Persons (in 1999) bolstered such claims, emphasising the need to think about older people's experiences within a framework of choices and rights, and this has been further underlined by debates over implementation of the Human Rights Act. Older people have increasingly organised themselves to campaign on issues of equality in areas such as access to health and social care, housing, income and employment rights. Social scientists have also become increasingly interested in the experience of ageing and in the policy implications of an ageing society. Alongside these developments, we have seen the emergence of a strong movement of disabled people, campaigning for choices and rights on many similar issues.

National organisations for older people (such as Help the Aged and Age Concern England) have launched campaigns for greater rights in relation to hospital treatment, inclusive housing and quality of life. Yet, few of these campaigns make explicit reference to disability rights issues. Disabled people's groups have made considerable advances in claiming their rights – for example, through the 1995 Disability Discrimination Act and the Disability Rights Commission. However, progressive disability policies continue to emphasise the needs of younger people rather than older people. While Government policies (like Labour's 'New Deal') and public debates about disability rights have been preoccupied with issues of employment, most disabled people are over retirement age. The starting point for this pilot study was to consider the views and priorities of local organisations working with older people within this policy context.

Objectives

Specifically, we planned to (a) identify the issues and concerns of importance to local and national groups representing the claims of older people and to contextualise these claims within the framework of British disability policy making, (b) explore commonalities and differences in the representation of claims to social inclusion by older people's groups and those of the disabled people's movement, emphasising the kinds of discourses used by different groups to represent similar claims, (c) conceptualise these findings as a basis for future research and theoretical development in the field of disability and ageing. These were clearly ambitious targets for a six-month pilot project and it was necessary to be realistic about the range and scope of the research from the outset.

Our decision to focus primarily on the perspectives of local voluntary organisations enabled us to achieve the data collection required. By adopting a reflexive approach early in the research process, we were able to revise our sampling targets and to collect more data than we had originally intended, allowing for a more

thorough examination of key informant perspectives. We were able to present some of the richness as well as the breadth of this data through empirically based and theoretically grounded research publications. In this way, we were able to highlight the significance of local data in the context of national debates and the sociology of ageing. The opportunity to publish work in the context of both disability studies and ageing studies has we believe enhanced the potential impact of our attempt to raise the profile of older disabled people across disciplines.

Reflecting on the data and its policy context enabled us to generate some initial theoretical constructs for future development. In particular, we were able to highlight important commonalities in the construction of disability and old age, for example, as perceived dependency and loss of autonomy. Significantly here, we were able to further our understanding of the way in which both disability and generation are constructed through institutions and culture as negative categories in opposition to idealised notions of adulthood (based on autonomy and individuation in the management of risk over the life course).

Despite the clear commonality of interest between older people's concerns and those of disabled people's groups, we also identified a significant strand of discursive dissonance, suggesting a lack of conceptual and political resources amongst older people's organisations with which to articulate disability issues. We were thus able to identify potential areas for tactical and strategic alliance between older people's groups and the disability movement, as well as the potential barriers to such joint mobilisation. These are ideas that we hope to develop from the pilot project through future writing and research.

Methods

The project was carried out in a large metropolitan area of the North of England, covering a total population of some 700,000 people. According to 1991 Census figures, some 18.8 per cent of this population were over retirement age (including 7.1 per cent over 75) and of those aged over 75, 56.7 per cent were identified as having a 'Long Term Limiting Illness'. There are a large number of voluntary and statutory organisations working with this population of older people. Although the overall Black and minority ethnic population was relatively small (at six per cent) there are several wards with large and concentrated minority populations. A number of local groups have emerged in response to the specific needs of elders within these communities.

Due to the limited timescale for this exploratory piece of work, our emphasis was to collect data efficiently and in a targeted way. In preparing our proposal we had already identified a number of relevant organisations. These ranged from local branches of large national organisations to small self help groups and voluntary sector service providers. Access was facilitated both by our existing links with community organisations and by the existence of a local 'older peoples community care forum'. We particularly targeted groups within this umbrella organisation. We had previously elected not to include statutory providers in our research. We also excluded private nursing homes and day centres. Our initial sampling was therefore focused primarily on voluntary sector organisations established to meet the needs of older people in the community. We also chose to prioritise inclusion of groups serving minority ethnic communities, and groups specifically targeting older disabled people (as well as those serving the population more generally). In all, we identified 72 groups for this initial sample.

In order to establish the range, composition and activities of our sample, we sent a structured postal questionnaire with a covering letter to each organisation, outlining the purpose and background to the research. The initial survey questionnaire included items about organisational structure and services provided, about involvement in campaigning issues, about issues of perceived significance to older people, and about the particular population of older people represented or served by the organisation. At this initial stage, we chose to use relatively simple closed questions in order to maximise participation, and with a view to expanding on the issues identified through further discussion and interviews. This tactic appeared successful and, with some follow up phone calls, we received a total of 57 completed questionnaires (a response rate of almost 80 per cent). The majority of organisations also responded to our invitation to send documentary evidence of their role, structure or activities (such as annual reports, publicity leaflets, constitution, etc.).

An initial analysis of this data from the first phase enabled us to target more detailed work with a smaller number of groups. Reflecting on the responses received, we developed a theoretical sampling frame, prioritising six variables: age of organisation; national connections; involvement in campaigning; user involvement; the targeting of people with impairments; targeting of minority ethnic communities.

We also used the initial survey to develop our interview schedule and topic guide for the in-depth interviews. In comparison to the questionnaire, we adopted a much less structured approach to our prompts. Here, we sought to gain an insight into the kinds of discourses and constructions used by our key informants in talking about the role and function of their organisation, and in talking about the population of older people they sought to serve or represent.

At this stage, we reviewed our initial plans and elected to alter our proposed sampling for the qualitative phase. We had planned to visit 20 organisations and then to select key informants in 12 organisations for more detailed discussion. However, the quality of data from the initial visits (particularly the additional documentary material and follow up phone calls) suggested that we might move directly to in-depth discussions. After piloting the interview schedule with two groups, we moved directly to key informant interviews. This enabled us to increase the number of interviews to include all 20 of the groups chosen for an initial visit (in practice, 21).

Although adding to the data processing and analysis load, this strategy allowed us to obtain a wider coverage and ultimately offered more opportunities for comparison. In light of the richness of this data, we also elected to restrict our involvement with national organisations to informal discussions and online research (rather than conducting formal transcribed interviews). It is our intention to pursue this avenue of enquiry in more depth as part of future research. In summary, the practice of grounded theory and analytic induction led us to conclude that more benefit would be obtained in this short project by focussing more tightly and deeply on data from the local organisations at the centre of the enquiry.

Results

More detail about our results and findings are included in the project publications and outputs, particularly with reference to the richer qualitative data. Some of the following summary is also reproduced in those papers.

About the organisations

Of the 57 organisations that responded to the questionnaire, the vast majority (around 85 per cent) were formally established with aims and a written constitution.

This reflected that fact that formal foundation was often a condition of contracting for service contracts with local purchasers or applying for funding from external sources (such as the National Lottery Charities Board). Almost all of the organisations employed staff (either as volunteers or as paid workers) but there was a very wide variation in the numbers involved, ranging from two groups with only one staff member to a national organisation employing 6,000 people. The majority employed less than 15 staff.

Although at least one organisation had been in existence since the late 1870s, most were much more recent. More than three quarters of the groups that responded had been established since 1980 (the median year of establishment was 1990), with more than a third established between 1994 and 1996 (the most recently established organisation was around three years old). This bulge of new organisations during the mid 1990s can be explained in large part by local initiatives in response to the Better Government for Older People Programme. In particular, monies were made available for the establishment of new neighbourhood groups to identify and respond to the needs older people in neighbourhoods and communities, although more than 40 per cent (24) identified some kind of link or affiliation with a national organisation.

Around a third of the organisations claimed to employ a majority of older people, and the same proportion claimed to have at least one disabled employee (although there was a substantial amount of missing data on these two items). All but three of the groups had some form of management committee or controlling body and half of those who responded included a majority of older people on that controlling body. A similar proportion included at least one disabled person. One in five included more than 75% of older people on their controlling body. The likelihood of disabled people being present on management committees rose with the proportion of older people on those same committees (for example, amongst those with a majority of older people on their controlling body, the proportion including disabled people rose from a half to around two thirds). This is perhaps unsurprising, suggesting that organisations more representative of their older constituency were more likely to include disabled people.

More than nine out of ten organisations identified the provision of some kind of 'service' to older people (only two said they did not provide any services). The most commonly mentioned form of support was information provision (all but two of the service providing organisations claimed to provide information to older people). Leisure opportunities, support services and transport were provided by around two thirds of service provider organisations. More than 40 per cent provided some kind of learning opportunities, while between a fifth and a quarter were involved in housing and/or health provision. It is important to note that, in addition to some missing data, almost two thirds of organisations claimed to be providing services in the category of 'other'. This we explored further in our discussions with key informants, suggesting that many groups were involved in more specific services (such as the provision of equipment, rehabilitation, counselling, befriending, or decorating). Most of the groups were providing a range of different services and supports in response to assessed needs within their local communities. Indeed, the majority of organisations were providing services to older people in at least five distinct areas of concern.

Most of our responses were from neighbourhood-based organisations, seeking to respond flexibly to the perceived needs of older people in their communities. By comparison, several organisations were established to serve specific target populations (based, for example, on particular ethnicity or impairment labels). There was great variation in the size of population served or represented (ranging from 10 to

100,000 people). However, the majority saw themselves as representing less than 250 people, with almost a quarter serving less than 40 people.

All but four of the groups targeted older people in general (those that did not were impairment or disability specific groups). Some caution should be attached to the interpretation of these figures, as (in addition to some missing data) a number of organisations appeared to identify ‘target’ populations that reflected the current composition of their clientele rather than any purposive initiative to reach out specifically to people with that characteristic. However, it is relevant to note that three quarters of these organisations claimed to be targeting older disabled people, and that between a third and half claimed to be targeting people with specific impairments (such as dementia, visual impairment, hearing impairment, physical impairment, learning difficulties, or mental distress). Half claimed to target older people from ethnic minorities.

Constructions of old age and older people

Our data illustrated the variety of ways in which the groups constructed old age. These may be summarised under five headings.

Chronological old age

Most of the groups we studied identified a minimum chronological age for eligibility in their documentation, or in the course of our discussions, although this was often blurred in practice. In the questionnaire we asked about the actual age range of the population served. The majority (28 out of 54 responses) identified age 60 as the chronological boundary of their target population. In practice, several only worked with people slightly older than this. A further eight organisations identified age 55 as their minimum. In all, 80% identified age groups of 50 or over. The remaining 10 organisations worked also with younger people and included disability or impairment groups, working with people of all ages, and some groups representing minority ethnic communities. We explored the use of chronological age further in our discussions, suggesting that groups were often flexible with their stated age boundaries – particularly where they regarded younger adults as ‘vulnerable’, and specifically where they were disabled. By contrast, the disability groups were more likely to identify ‘older people’ with advanced chronological age (over 75), while minority ethnic groups tended to identify a younger boundary age.

Old age as biography, identity and personality

We did not set out to talk to older people about their individual biography and identity in relation to ageing in this project. Rather, we wished to focus on how those working in organisations serving older people thought about these things. There was a general consensus that older people tend to disassociate themselves from old age identity for as long as possible. Despite the high profile of ‘active ageing’ campaigns by national organisations, there was no direct reference to this idea amongst the local groups we spoke to. However, most of our key informants argued that the people they targeted were likely to resist being labelled as older, for fear of being perceived as dependent rather than leading active lives. Personality factors and the desire to maintain a sense of ‘independence’ were identified as key factors here. We address some of this aspect of the data in more detail in one of our published papers.

Old age as generation

A third broad construction was to identify older people with a more structural notion of old age (irrespective of chronological age). This kind of view relied less on identity or bodily ageing and more on labelling associated with the social relations of production and reproduction (e.g. those who had retired from labour force participation or those who had become grandparents). Such categorisations were culturally situated and had particular relevance for groups serving minority ethnic communities. For example, as one South Asian group put it: ‘Once a person is 45 they assume she has grown up kids and once they have grown up kids they class themselves as elderly anyway, even though they look young... especially the females. Once they get to 40 and over they tend to be classed as elderly especially if the female has a grandchild. She can be as young as 34 and have a grandchild and still be classed as elderly, its a cultural thing’.

Old age as the onset of impairment

The onset of old age was often associated explicitly with the onset of impairment. For example, five out of our 21 interviewees identified becoming older with specific disruptive impairment events such as dementia, broken hip, arthritis, high blood pressure, angina, stroke, heart attack, life threatening illness, mental distress, depression, panic attacks, or agoraphobia). The association between the onset of impairment and the onset of old age was generally explained in relation to physical functioning (for example, when people became unable to do ‘something that you perhaps previously took for granted’). In this sense, there was a clear differentiation between ‘more able’ and ‘less able’ older people.

The frequent use of physical or cognitive function as a defining factor led some groups of older people to be identified as ‘ageing’ earlier than others, due to the early onset of age-related impairment associated with poverty, living and working conditions and so on (for example, those who were homeless). In particular, some organisations serving minority ethnic communities suggested that Black elders might experience illnesses associated with old age at a younger age than white people.

Old age as loss of autonomy and control

The construction of older people as those with functional impairments overlaid a more general theme in the data, connecting old age with loss of autonomy and with perceptions of dependence. Here, the key category appeared to be people within the broad age group who became less able to function autonomously or without assistance (i.e. ‘independently’). This was also a key theme in the way that organisations talked about disability (see later) and provided the most obvious thematic linkage between simultaneous constructions of older people and disabled people. However, impairment was not the only factor here and bereavement (specifically the death of a spouse) was clearly identified as a trigger for dependence in similar terms. Some argued explicitly that old age begins with a loss of control following impairment or bereavement, acknowledging a loss of relational interdependency as the key. The construction of independence as autonomous physical functioning has been particularly important in our attempts to theorise the parallel relationship between disability and old age, on the one hand, and adulthood on the other. These are concepts that we are currently developing in work for publication.

Constructions of disability and disabled people

All of the organisations involved in our research claimed to serve substantial numbers of people with perceived impairments (in many cases a majority), irrespective of the client group identified by their constitution. However, few showed any awareness of current disability equality issues or debates. Most of our informants had not thought about these issues before and some felt quite uncomfortable in using the term disability as applied to the people they sought to represent. The following four themes summarise the ways in which disability was constructed within organisations.

Visibility and severity of impairment

In some cases, the term disability was used only to describe older people with visible physical impairments: for example, 'I don't like to label people. I wouldn't label somebody as having it unless it's physical and you cannot avoid, and the person has got the appearance of whatever...when you label people disabled, you put them in that category that makes other people see them different'. In this sense, significant physical mobility impairments were sometimes perceived as 'real disability' - 'Most of them...have a disability of some kind...No-one comes in calliper or in a wheelchair. Nobody is as bad as that. They come with sticks...' (later, we highlight the distinction made with impairments regarded as 'normal' in old age).

A functional view of disability

As with definitions of old age, there was a strong association between disability and functional dependence (perceived as arising from impairment rather than disabling barriers). People were commonly viewed as disabled if they could not do certain things *without assistance*. In functional terms, the visibility or nature of impairment became less important. For example, someone with heart disease was seen to be disabled, 'because they can't climb stairs, there's lot of things that they can't do. Just because its unseen, it's not visual, doesn't mean to say they're not disabled'. In this sense, 'Elderly people may be disabled whether or not they class themselves to be'. They are disabled because they, 'become less able to maintain their own independence, reliant on other people, and become disabled but it's not from birth'. Within some groups disability was largely defined by their own capacity to accommodate and support people in service provision: for example, only catering to those who can, 'look after themselves when they are here'.

Disability identity

Conversely, disability, like old age, was sometimes viewed more as an individual identity issue: 'When they say they are disabled...the charity as a whole would encourage all of our staff not to make the decision for a person but to let the person make that decision themselves'. However, the emphasis seemed to be less on positive identification with disability identity and more on perceptions of personality and intrinsic motivation to remain independent: 'We have what I would consider to be *really* disabled older people who are active, involved, who push themselves despite their disabilities. We have others and the first sign of an ache or a pain that's enough to say I won't be able to do this any more, or I need home care'.

What about the social model?

As the preceding analysis suggests, we found little apparent awareness of the social model of disability among older people's groups (and there was no direct

reference to this concept in any of the interviews or documentation). As one informant commented, 'I don't know how the disability movement would define it, I've never asked the question'. Rather, the construction of disability tended to reflect a more medico-functional model. Given the current high profile of social model rhetoric in policymaking and advocacy with younger adults, this has significant implications for the disability movement, highlighting an apparent lack of disability equality and advocacy work with older people.

However, we did find evidence of social model thinking in the definition of barriers facing older people with impairments. For example, 'someone who needs a hearing aid, without that aid, they would be disabled', or, 'We often ask if they can manage independently in the bath room to bathe themselves and they'll often say well I could manage better if I had a bath seat or if I had a hand rail. So they might not necessarily be disabled because they are acquiring these things'. There was then some recognition that disability might be contingent upon the removal of barriers and on available levels of support. Thus, 'if it wasn't for our group they would be less able to do things that they wanted to do, to enjoy life or to have a quality of life, if they were to have to fend for themselves in this type of society. That sounds really quite awful really but the society that we live in is not very enabling'.

Disability and old age

Taking into account the preceding sections, we also examined the combination of disability and old age through the construction of older disabled people. The following four themes summarise our findings in this area.

Impairment and disability across generations

Although disability was viewed variously, within medical, functional or social models, it was often seen to apply equally to people of all ages. Half of the organisations we visited (11 out of 21) considered everyone with significant impairment to be disabled, whether or not this was related in any way to ageing - '...whatever illness they have is disabling them from being able to take more social activities or quality of life they've had before', or, 'It's still a disability for an older person...whether its old age related or not. It's still a disability in our eyes because they are disabled from doing something they want to do'. As another group told us: 'Just because people are getting older and physically less able does not mean they don't want to enjoy their lives.... As far as we are concerned, that is a disability'.

Age-related impairment is different

A similar proportion had a different view. For them, people with impairments acquired in old age, or those normally associated with ageing, were not necessarily seen as disabled. For example, 'I would not necessarily say an older person had a disability if they have got age related hearing loss. I would say well that's something that happens with age. It is like your hair going grey'. The same logic was applied to functional as to medical definitions of disability. For example, people were viewed as disabled where they were seen as unable 'to carry out what *a normal elderly person* could do'. In this sense, certain forms of medical or functional impairment were not seen to deviate from generational norms of old age (i.e. as opposed to norms of adulthood). Nor were they viewed as significant forms of biographical disruption to normative life course narratives. Rather, such impairments were viewed as part of the corporeal or generational habitus of older people. This is also an issue that we have explored in our project publications.

Older disabled people have different needs

Older people with significant impairments were sometimes regarded as having different needs from younger disabled people. For example, ‘you wouldn’t treat an older person with hearing loss the same way as you would treat a life long Deaf person’ (the suggestion here being that they would have no need to learn sign language ‘at their age’). Alternatively, older disabled people were seen to have greater needs than younger people, for example, because they had not ‘learned to live with it’.

Discursive dissonance and dialogic resolutions

In exploring some of these issues, our research highlighted several instances of discursive dissonance in the accounts of key informants. Most starkly, we heard apparently contradictory accounts, which began along the lines that ‘no-one here is disabled’ but which concluded that ‘everyone here is disabled in some way’. Our initial analysis suggested that some of the interviewees were openly struggling to disentangle individual and social model approaches to disability yet lacked the linguistic or narrative resources to express this easily. However, in dialogic interaction with an interviewer who was herself a disabled woman, and sympathetic to the social model, they were sometimes able to resolve this dissonance. This finding requires a more detailed discursive analysis than can be presented here but indicates that there may be much fertile ground for disability equality training within older people’s groups, despite an initial resistance to critical disability discourse.

Issues of concern

While there is some considerable overlap in the issues on which older people’s groups and disabled people’s groups have campaigned, the ways in which they have represented apparently similar claims differ. For example, where the UN Year of Older People envisages a ‘society for all ages’, disabled people’s groups have sought to create an ‘enabling society’. Where disability groups have campaigned for ‘accessible housing’, older people’s groups have advocated ‘housing for life’. Where older people’s groups have objected to ‘do not resuscitate’ (DNR) decisions based on age, disabled people’s groups have highlighted the withholding of life saving treatment for people with impairments. Where older people’s groups have argued over ‘cold weather payments’ on grounds of age, disabled people’s groups have made claims for recognition of the ‘additional costs of impairment’. There are numerous parallel examples in relation to social services, transport, environmental access, health care and so on. Although the differences between the representations and discourses used to legitimise similar claims may appear small, they suggest an underlying distancing of older people’s claims from those of ‘disabled’ people (and vice versa).

We asked organisations responding to the questionnaire to identify the kinds of issues that had been most important to them during the past year, by rating a list of key issues using a simple three point scale (very important, important, not important). Although somewhat simplistic, there was a very strong identification with issues of ‘independent living’, ‘health’ and ‘active ageing’, as well as with social and leisure activities. The apparently high level of concern with independent living issues might suggest a substantive area of overlap in the interests of older people’s organisations and disabled people’s organisations.

By contrast, employment was clearly of least concern to local groups (along with sex discrimination and lifelong learning). Pensions were also rated as ‘very important’ by relatively few organisations, although ‘benefits’ issues were clearly important to many more. Here, there is a considerable difference between the

priorities of local and national organisations representing the needs and claims of older people. Bearing in mind the focus on a largely retired population this may be unsurprising, although national advocacy groups have been very concerned with employment and pension rights recently.

The number of organisations ranking particular items as ‘very important’ seemed to be fairly consistent across our sample and was not obviously affected by other variables (such as the representation of older people on the management committee or the specific targeting of disabled people). There was however a tendency for organisations responding to minority ethnic concerns to rate health issues as ‘very important’. The discussion of policy issues is discussed in detail in one of the project papers – drawing specific attention to: Independent living, Information and advice, Housing, Isolation and social activity, Mobility and transport, Health and active ageing, Incomes, Employment and lifelong learning. Suffice to say that there was ample evidence of substantive areas of common ground in the interests of disabled people’s organisations and those representing older people.

Campaigning

The questionnaires suggested that almost three quarters of organisations had some involvement in campaigning (73.7%). Newer organisations were no more or less likely than older organisations to identify an involvement with campaign issues. However, those groups established in the mid 1990s were much more likely to identify campaigning amongst their activities. In this sense, the character of organisations established in response to the Better Government Programme appeared to suggest a more politicised potential.

Overall, 21 organisation (37.5%) identified some kind of disability campaign activity. However, excluding those who were not involved in any kind of campaigning, this rose to around half (51.2%). So, there was some evidence of a good deal of potential for political crossover between older people’s groups and disability issues. Of those that did not campaign on older people’s issues (19 organisations) only one was campaigning on disability issues (this being specifically a disability organisation) while four others were primarily concerned with carers’ issues. The remainder were mostly small organisations providing limited support to local older people in their neighbourhood (such as lunch clubs).

We had sought to include representation from groups representing minority ethnic communities and our initial sample reflected this, with around 16 organisations (29.1%) claiming to have some involvement in campaigning on race or ethnicity issues. This sub group was particularly interesting, as campaigning on these issues seemed to be highly indicative of involvement in other campaigns. For example, all of these 16 groups said they were involved in older people’s campaign issues and 14 of them (87.5%) were involved in disability campaigns (this was more than double the rate of involvement for all organisations). The rates for involvement in gender issue campaigns were also around double the average amongst this subgroup.

Taking this analysis further, we examined the data on groups involved in campaigning on gender issues. The numbers here were smaller (only 9 organisations). However, we again found extremely high rates of participation in campaigning on disability and other issues (all but one group were involved). Working backwards, this time ignoring those organisations involved in campaigning on race and gender issues, we found only 15.8% (6 out of the remaining 32 organisations) claimed any involvement in disability campaign issues. The sample size is too small to draw any statistical conclusions but these findings merit some careful attention. Does

politicisation in the area of race/ethnicity and/or gender issues tend to predict a wider politicisation within older people's organisations on issues such as disability? Clearly, our findings would suggest that this is the case. No other factor was as predictive of disability campaign involvement (including the targeting of, or provision of services to, disabled people as clients).

Activities

This was a short pilot project, focused on data collection and indicative analysis. The opportunities for additional activities during the six-month funded period of research were therefore very limited. In addition to the outputs cited below, we were able to feed back findings to the participant organisations and others through a newsletter and project website. It is our intention to present findings from the research to a local dissemination event and to academic conferences. We have also begun a process of information exchange on the potential for collaboration with other European researchers, particularly in the Nordic countries.

Outputs

Given the scale of the project, our research yielded a substantial amount of data (57 questionnaire returns, documentation on organisational structure and function, field notes from visits and transcripts from 21 interviews with key informants in voluntary sector organisations working with older people). The questionnaires and documentation are primarily of local significance (mapping the range and extent of voluntary sector activity). The interview data provides some original insights into the way that voluntary sector organisations construct the relationship between old age and disability – and how they perceive the needs of older disabled people. Agreement has been made for registration of the latter with the ESRC Qualidata Archive.

Our emphasis in this short project was: to summarise findings within a national policy context; to begin the development of a theoretical framework for interpreting these findings; and to raise questions for further research. In order to achieve this, we have completed three academic papers for publication. The first arises from a review of national policy making, involving original research into the representation older disabled people in national policy communities (accepted for publication in a special issue of *Policy & Politics*). The second addresses qualitative data from the interviews, in the context of culture and identity, with an emphasis on revealing discourses of the ageing body, otherness and dependence (to be included in a forthcoming edited book, published by Longman). The third paper draws on data from the survey and interviews highlighting issues of common concern and policy relevance to older and disabled people's organisations, and addressing the potential for political alliance (recently submitted to *Disability & Society*). In addition, the project has been selected by *Community Care* magazine for a review to feature in their 'research into practice' section. This piece will summarise the research findings and highlight the practice implications for social workers and practitioners working with older and disabled people. The findings and theoretical developments will also contribute to ongoing ESRC-funded work by the principal researcher, as part of a chapter on old age in a forthcoming sole-authored textbook (to be published by Polity).

References:

- Priestley, M. (2002, in press) Whose Voices? Representing the claims of older disabled people under New Labour, *Policy and Politics*
- Priestley, M. (2002, in press) 'It's like your hair going grey', or is it? Impairment, disability and the habitus of old age. In, S. Riddell and N. Watson (eds) *Disability, Identity and Culture*, Longman
- Rabiee, P. and Priestley, M. (under review) Same Difference?: older people's organisations and disability issues, paper submitted to *Disability & Society*
- 'Building Bridges', a series of newsletters about the project for organisations working with older people.

Impacts

The immediate impacts of this small pilot project were necessarily limited. However, we were able to discuss the findings with those responsible for co-ordinating local services to older people and with local disability organisations. The outcome of this process has been to initiate discussions with a view to increasing the profile of older disabled people within generic services and improving disability access to those same services. We hope to continue our involvement with this process, through a local dissemination event and advisory input to service planning. In addition, we hope that the publications and the review in *Community Care* will lead to service and advocacy impacts more widely.

Future research priorities

Our findings raise a number of significant issues and questions for further research. There is clearly considerable scope for involving organisations of and for older people in research and debate about disability issues, and much common ground upon which to base that involvement.

- Our research did not directly address the experience and biography of older people. However, we consider this to be a fruitful area for future research, and that researchers working with older people might be encouraged to draw a critical disability studies perspective more clearly into their analytical focus.
- It will also be important for disability researchers to seek the greater involvement of older people and their organisations in disability research and policy debates. This is currently a significant area of under-representation in disability studies. There may however be some work to be done in finding the language and agendas to bring such groups into positive discussions, and research may need to be combined with some disability equality and advocacy work.
- A parallel investigative study with disabled people's organisations, about their responses to older people and ageing issues would considerably complement our findings. We found some anecdotal evidence of a resistance amongst disability groups to engage with older people, despite the fact that older people are in a majority of disabled people in Britain. This merits more investigation.
- Within a national policy context, there is a considerable task for researchers in disentangling the various frameworks of provision for 'older' and 'disabled' people. The current situation exhibits a high degree of complexity and confusion within and between these administrative categories. In particular, there may be some considerable merit in cross-national research and policy development within a European context on these issues.