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Does Size Matter? The benefits and challenges of voluntary sector partnerships in dementia service provision for South Asian communities in England

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Abstract

In response to the need for improved access to dementia services for minority ethnic communities, the Alzheimer's Society piloted, in 2014, the Information Programme for South Asian Families (IPSAF), an adapted version of its existing course for carers. It delivered this in partnership with local black and minority ethnic community and faith organisations, a new approach for the Alzheimer's Society. In most cases, the partnerships formed were strong and effective, and have given rise to ongoing plans for joint working that bring benefits to both the local organisations and the Alzheimer's Society. However, the current realities of UK voluntary and community sector dynamics raise questions of ownership and issues around how to establish genuine partnerships. In this article, we reflect on what the IPSAF experience indicates about the potential for equitable partnerships between small and large organisations, and draw out lessons for building effective, mutually beneficial relationships.

Key words: black and minority ethnic • Alzheimer's disease • health • third sector

Introduction

The Third Sector has historically played an important role in tackling complex, multifaceted problems, through bringing together diverse skills, knowledges and communities. The provision of dementia services to Black and Minority Ethnic (BME) communities is one such issue. These communities face an anticipated seven-fold increase in numbers of people living with dementia over the next forty years, compared to a two-fold increase across the whole UK population (All-Party Parliamentary Group on Dementia, 2013). However, BME communities are already severely under-represented in the take-up of dementia services. Contributing factors include: low levels of awareness about dementia, high levels of associated stigma within BME communities, lower rates of formal diagnosis, higher levels of late diagnosis, lack of knowledge of available services and a lack of culturally appropriate services (Giebel *et al*, 2015; Moriarty *et al*, 2014; Johl *et al*, 2014; Truswell, 2013). Furthermore, despite the considerable diversity within BME communities with regard to health and service use, experiences of BME groups have often been presented as if homogenous within health research, arguably as a result of ethnicity data not being collected in a systematic manner or being poorly reported.

Alongside formal health services, the third sector in England and Wales provides a variety of dementia support services, including social groups, services for carers and information provision (variations in UK social policy mean that the third sector in Scotland also plays a significant role in direct care post-diagnosis). Expanding the currently low provision of dementia services for (and take-up by) BME communities requires a considerable range of competencies including dementia expertise, facilitation skills, local community connections, and cultural understanding. It is likely that partnerships between established dementia providers and locally rooted BME Voluntary and Community Sector (BME VCS) organisations could offer this range. This article explores the effectiveness of such partnerships in transforming outcomes for often excluded and marginalised communities, through the case study of the Alzheimer's Society's Information Programme for South Asian Families (IPSAF). However, in the context of an increasingly marketised third sector that arguably encourages competition rather than collaboration (Lyon, 2013; Eikenberry, 2009; Ryan, 1999), the case study also offers insights into the extent to which it is possible for a large organisation to collaborate on an equal footing with smaller organisations.

Context: voluntary sector partnerships and the BME VCS

There is a great deal of literature reflecting on the dynamics of cross-sector partnerships, specifically VCS / public sector collaborations (e.g. Milbourne, 2009; Carmel & Harlock, 2007; Rummery, 2006, Lewis, 2005, 1999), but less attention has been paid to the dynamics of partnerships *within* the voluntary sector (see Body, 2015). Importantly, the context for such collaboration has been shaped by a proactive state agenda, which called for Third Sector cooperation but in practice arguably encouraged competition. Based on an assumption of shared values (Home Office, 1998), New Labour's emphasis on state partnership with the VCS intensified an increasing emphasis on the primary role of the sector as service provider (e.g. Home Office, 2004). This was further embedded in the approach of the Conservative-led coalition. Significantly, this was now decoupled from New Labour's assumption of shared state / VCS values, and replaced with an ideological commitment to a 'smaller state' (Conservative Party, 2010). Thus, the focus moved towards shifting (much reduced) resources away from the public sector and towards independent service provision, including by the VCS, which is now increasingly expected to compete with 'for-profit' organisations as well as with public service providers (Cabinet Office, 2010:5-6). In this context, there is inevitably an impetus towards VCS organisations positioning themselves to become 'commission-ready', with associated implications for intra-sector collaboration *and* competition.

One consequence is an increasing tension between 'choice' and 'voice': between a government-facing role as commissioned service provider and traditional VCS functions, in particular advocacy, which can involve a willingness to challenge the state as well as to collaborate (Kelly, 2007). It has been suggested that this is a particular issue for larger third sector organisations which, while effectively positioned for service provision across a broad range of issues, 'risk social mission drift, confused accountability, and erosion of charitable

values' (Bruce & Chew, 2011). Importantly, VCS organisations more oriented towards service delivery (representing 'choice') may impact on the position of more mission-focused organisations (representing 'voice') within what is increasingly understood to be a VCS 'market'. Thus, some smaller and medium-sized VCS organisations perceive a 'triple threat': organisations with little experience of specific service sectors moving into new 'markets', entrepreneurial 'non-profits' whose low overheads are based on problematic practices such as casualised labour, and very large charities squeezing out local expertise and specialist services (Milbourne & Murray, 2014). In addition to tensions between organisations, this environment may also lead to internal tensions (particularly in larger national charities), between the competing dynamics of 'mission' and national 'market' position.

In this context, collaboration between more mission-focused VCS organisations may help build supportive 'self-help' relationships to share resources, expertise and skills, stemming from a value-based commitment to meet the needs of specific marginalised communities. However, while larger organisations with a formal profile and established networks across the voluntary sector are well-placed to build relationships which protect their position, micro community organisations appear to be especially vulnerable to the dynamic of increased competition within the sector (Body, 2015). To illustrate, size strongly influences an organisation's ability to attract funds – or even survive (Backus & Clifford, 2013; Body, 2015). Therefore, the nature of intra-sector partnerships is central to the outcomes achieved (Baker & Cairns, 2011), both for the organisations involved and, by extension, for the communities the partnerships are designed to serve.

The BME VCS represents a clear example. Historically, these organisations have played a crucial role in both meeting their communities' needs and pressing for equal provision more widely (Craig, 2011). However, it is significant that this element of the sector is typically made up of smaller, often underfunded and already marginalised organisations, and frequently struggles to access funding on an equal footing with the mainstream VCS (Chouhan & Lusane, 2004). Illustrating the issues described above, there is a clear desire from BME VCS organisations for capacity-building support (including stronger links with organisations already involved at a strategic level), which might enable them to be more successful in attracting funding (Netto *et al*, 2012). However, the third sector context alerts us to possible pitfalls. In this vein, the experience of BME VCS organisations partnering with larger cancer charities may sound a warning note. Practitioners from the UK National BME Cancer Alliance recognise the value of intra-sector collaboration but also describe some dangers, including a sense that smaller BME organisations can be expected to supply specialist information and expertise, and take a lead on recruitment and communication with BME populations in joint initiatives, without receiving full acknowledgement or receiving an appropriate share of resources (thereby enabling larger less specialised organisations to gain access to new populations and expand their reach) (Tilki *et al*, 2015).

This paper explores the potential benefits and challenges of intra-sector partnerships between larger and smaller organisations, through the experiences of local BME organisations co-delivering a dementia service for South Asian families with a large national charity.

Case study: the Alzheimer's Society's Information Programme for South Asian Families

The Alzheimer's Society's Information Programme for South Asian Families (IPSAF) is a culturally tailored adaptation of the Alzheimer's Society's Carers' Information and Support Programme (CrISP). CrISP was developed in 2010-2011 to deliver information to carers whilst providing peer support. An evaluation of the programme in 2013 found it to be successful in improving carer knowledge of dementia and the peer support to be highly valued (Barnes *et al*, 2013). IPSAF was then developed to meet a further objective of the CrISP programme: improving access for BME communities. An initial focus on South Asian communities (defined as those who originate from the southern part of the Asian continent, for example India, Pakistan, Bangladesh and Sri Lanka), as the largest affected BME community, was intended to ensure that the course met the specific needs of participants. To date, IPSAF has been delivered over two pilot phases. Phase 1 was delivered at 5 sites between January and March 2014, phase 2 at 15 sites between September 2014 and March 2015.

The aims of IPSAF are to improve the knowledge, skills and understanding of South Asian families caring for someone living with dementia. Additionally, it is hoped that the wider South Asian communities will benefit through information-sharing by participants. IPSAF is intended for friends and family members who are current carers, though a formal diagnosis of the person cared-for is not necessary for a friend or relative to attend. In practice, around a third of the courses were attended solely by carers; at other sites carer participants were joined by community members attending out of general interest.

The IPSAF programme reflects the desire of a leading provider in the field, the Alzheimer's Society, to address gaps in provision for BME communities. Recognising the limits to their culturally specific expertise, the Alzheimer's Society worked with local BME community and faith organisations to deliver IPSAF. A new approach for the Society, these partnerships were grounded in a desire to provide better, more inclusive services, through combining their dementia expertise and profile with the local knowledge and cultural expertise of smaller BME VCS organisations.

Public consultation events were held in London, East Midlands and West Yorkshire to inform the development of IPSAF in order to meet the informational and support needs of South Asian families. These were mainly attended by people living with dementia and their carers but also included community and faith leaders. National Alzheimer's Society staff then developed scripted course materials, with the aim of ensuring consistent delivery at local level. Local Society branches were invited to apply to pilot IPSAF in

their area. Once sites were selected, participating branches identified local BME organisations, and invited them to help deliver the programme in their locality. Community partners were mainly South Asian or BME organisations working in the fields of dementia, carers' support or health, plus a GP service, two community centres and a mosque. With one exception, the organisations had not worked together prior to IPSAF, and all but two had not offered specialist dementia services prior to their involvement with IPSAF.

The partnerships operated at two distinct levels, organisation of the programme and its delivery. First, the local Alzheimer's Society manager approached a recommended organisation and built links (in most cases, following a word of mouth recommendation). Partners were invited to provide a co-facilitator and, if required, a separate interpreter (IPSAF is delivered in English, and translated if necessary). Detailed planning was then handed over to the CrISP facilitator(s) and BME VCS co-facilitator(s) who would together deliver the course.

Research methods

The findings presented here are based on an evaluation of phase 2 of IPSAF, funded by the Alzheimer's Society and carried out independently by researchers in the School of Dementia Studies at Bradford University between June 2014 and March 2015. The evaluation was based primarily on a sample of 8 of the 15 courses that took place during IPSAF phase 2, in a variety of locations across England. Two of the evaluated courses were attended by carers only, in 3 courses carers were the majority, and in 3 courses carers were a minority.

We took a pluralistic approach to generate a multi-faceted understanding, selecting methods that would allow understanding of subjective perspectives (focus groups and interviews), balanced with observation (of course delivery and co-facilitator familiarisation and support sessions), and a knowledge quiz to allow some quantification of knowledge gain. An experienced multi-lingual researcher co-facilitated all focus groups. Family interviewees were invited to participate in English, Hindi, Urdu or Punjabi. Focus groups and interviews were audio-recorded, and fully transcribed. All qualitative data were inductively thematically analysed. An outline summarising methods and participants is given in table 1 (see Parveen *et al*, 2015 for more detail on methods and specific outcomes). The findings presented below draw on analysis of all data sources.

Research methods table here

The partnerships in practice

With the exception of the two community organisations which already provided tailored dementia services, IPSAF represented a significant extension of existing provision for both partners, through the combination of two distinct sets of knowledge and experience: the development of BME tailored services from an

existing generic service for the Alzheimer's Society, and the addition of dementia support to an existing range of services for BME communities for the community partners.

For the Society nationally, the IPSAF partnerships were intended to enable future joint working at local level, meet a need for local staff to learn about communication with different communities and share knowledge about dementia with South Asian organisations. Local facilitators emphasised building better connections between the Alzheimer's Society and local communities as a primary aim. Thus the partnerships would both help the Society provide better, more inclusive services, and help their staff develop skills and cultural competency. In most cases, motivation for partner organisations came through a close fit with their organisational aims of providing health training, services and related activities to marginalised communities. For some, the value of working with a large, well-known organisation was seen as an additional organisational benefit, which might improve access to strategic contacts and resources. The exception was the only mosque involved; while supportive of IPSAF, it did not match their primary aims as a religious organisation. In this case, their involvement waned, providing a venue but not participating in facilitation. In all the other sites, community partners participated fully throughout the course of the project.

While the degree to which the course met the (connected but distinct) aims of local communities, the Alzheimer's Society and community partner organisations varied between sites, in almost every case strong and effective partnerships were formed. Where this happened, participants gained a better understanding of dementia and access to improved peer support, the Alzheimer's Society benefited in terms of cultural learning and organisational development, and the partner organisations benefited in terms of increased recognition and extending the scope of their work (though here the experience was more mixed). We discuss outcomes for each of the three stakeholder groups in more detail below.

Community outcomes

Overall, the partnership approach of the IPSAF programme was successful in generating positive outcomes for participants and their wider families, including the person with dementia (for more detail, see Parveen *et al*, 2015). The most significant outcome was a marked increase in knowledge about dementia, which helped participants better understand the perspective of the person with dementia. This had benefits for the person with dementia, as it led to changes in care practices, such as more positive communication styles and more involvement in day-to-day activities, and for carers themselves, who reported a reduction in frustration and stress as a result of their improved understanding. Some described feeling more confident in their role as carer, and more able to ask health professionals for support. Participants also strongly valued the mutual support gained through IPSAF. For most, the course greatly improved their awareness of available services. Many accessed practical support as a result, for example help with power of attorney paperwork, a carer's assessment, or specific advice from the Alzheimer's Society. However, less

use was made of social support services such as well-being cafés, despite some expressed intentions (and some evidence that such services would be welcome, given the value placed on IPSAF itself as a source of peer support). There was also evidence that participants shared information with family members who had not attended the programme themselves, though unsurprisingly the benefits for these carers were less marked. Finally, there is some indication that the experience of talking about dementia in a supportive environment with peers from a similar cultural background helped some carers feel more confident in speaking about their own situation with relatives, friends and neighbours (often difficult given the stigma frequently associated with dementia, as noted above).

Importantly, *every* community member participating in the course reported that they found it helpful. While IPSAF is intended for people caring for someone living with dementia (and the degree to which facilitators responded positively to more mixed groups varied hugely), it is noteworthy that non-carers also reported positive benefits. Furthermore, the carers who participated did not feel that the presence of non-carers had a negative impact on their experience. Rather, they saw positive benefits to a wider discussion of dementia within their community. As one put it:

'The fact that I was going to go to a place where there were other Asian people, and we were all going to sit, and we were all talking about dementia, that in itself, was just massive.'

(Carer participant, family interview, June 2014)

Given the consistency of benefits gained by participants, one significant factor in maximising these positive outcomes, therefore, was the degree of success achieved in recruiting participants. This varied markedly across the sites, with between 6 and 17 people attending each course. Successful recruitment strategies relied heavily on community partners. Indeed, in most sites, word-of-mouth contact through the partner organisation was the *only* effective route to participation, despite use of other means including posters, leaflets, email publicity and contact with formal services (across all sites included in the evaluation, only 2 participants were reported as recruited through other means). Thus, recruitment was difficult in the site where the community partner did not actively participate.

All sites stressed the importance of trust between the partner organisation and South Asian community members:

'You need to build that rapport with people. You can't just say, "I'm going to invite you to this, can you come?" With Pakistani people, you need a good relationship with them and trust, and then they will come. Otherwise they will not come.' (Community partner interview 3, December 2014)

Community partners also contributed knowledge of community needs to the recruitment process, for example, allaying carers' fears of being judged. In a similar vein, several community partners made a case

to the Alzheimer's Society that facilities to enable the person with dementia to attend (not offered to CrISP participants) were needed for IPSAF, due a lack of culturally appropriate sitting services. This intervention was felt to make a significant difference to participant numbers in those areas.

Within the course, positive outcomes rested on dementia expertise provided by Alzheimer's Society staff (plus, in 2 cases, the community partner, who also worked in dementia support) and local and cultural knowledge, largely provided by community partners (plus, in one case, the Alzheimer's Society facilitator, who also belonged to a South Asian community). Importantly, community partners tailored the course content for their local audience, as one Alzheimer's Society facilitator emphasised:

'Without her knowledge it wouldn't have been what it was, definitely, because she made it very much tailored to the right audience that was here, and she had the knowledge to do that.'

(Alzheimer's Society facilitator interview 6, December 2014)

This was particularly marked in sites where the partner had some dementia knowledge, but was evident to differing degrees in every site where community partners were present. Contributions included introducing discussion of community-specific risks such as the loss of English as a second language, suggestions for dementia support around culturally specific food habits and daily practices such as prayer, and giving specific examples from South Asian communities. For example, the community partners showed an appreciation of cultural norms, which might (for example) influence the availability of support from other family members. While the course was adapted in terms of venue, publicity and the use of South Asian protagonists in course materials, the content itself was more generic (indeed, described by one Alzheimer's Society staff member as *'literally CrISP but with different names'*, interview 4, December 2014). Therefore, the content and understanding supplied by community partners were highly valued by participants:

'There was lots of things, as soon as they said it, everybody just looked and smiled or laughed ... Just went, oh, you're having a joke, that's not going to happen, but they knew, in the way that they said, yeah, we know that this happens, but you still need to get everyone together. They understood how it happened.' (Carer participant, family interview, July 2014)

The importance of this was underlined in the site where the community partner did not contribute to delivery, as one participant explained:

'I wanted a few more questions really to be answered, some more [culturally specific] examples to be given, that's what I was looking for, because it's very difficult on my part to ask somebody for any help or something, you know.' (Carer participant, focus group, December 2014)

It is therefore clear that the dementia expertise provided by the Alzheimer's Society and cultural competency provided by the community partner were both essential and complementary factors in

generating positive outcomes. Facilitation skills and community development experience also played an important part, and both sides of the partnership provided these in different sites.

Outcomes for the lead organisation

Beyond improved service delivery, there is strong evidence that Alzheimer's Society staff gained significant cultural knowledge and understanding, including learning about how to work more effectively with local communities. This was likely to benefit the wider work of the Society. In most cases, the partnerships also built ongoing connections between the Alzheimer's Society and local South Asian organisations, which is likely to generate future joint working in addition to IPSAF. There is some, more limited, evidence of stronger connections with South Asian communities beyond the partner organisations, though this varied across the different sites.

Cultural learning for Alzheimer's Society staff came through two sources. Firstly, all participating staff (including community partners) were required to attend a two-day cultural competency course. Secondly, Alzheimer's Society staff learned from community partners and participants throughout the course. Overall, Society facilitators found the cultural competency training valuable for every aspect of their work, and suggested that it should be core training throughout the organisation. However, there was some recognition that a great deal of its value would be lost without the participation of community partners:

'The course had a lot of ladies from different cultures, and they were saying it from their point of view. It was really good. I really enjoyed that course. And I'm glad I did it because I'm a support worker anyway ... It's a training course, I think, that everyone should do.' (Alzheimer's Society facilitator interview 2, December 2014)

For many Alzheimer's Society facilitators, IPSAF was their first in-depth experience of working with South Asian communities. Accordingly, it proved a concentrated learning opportunity, as described here:

'It's been an interesting experience, practically learning about working with the community here as well, especially since I'm quite new and part of my role is trying to develop services with the BME community locally, it's been interesting to actually start interacting, getting to know some people from the community and to see first-hand how difficult it is to attract people and make you think about alternative ways of doing that for the future.' (Alzheimer's Society facilitator interview 6, December 2014)

Learning included 'debunking myths' as well as improved knowledge of cultural norms around food and families, appropriate venues, and the need to adapt other services to be more accessible:

'I think it is really good on a personal level ... being able to speak to a lot of people, understanding where carers are coming from. Like this fallacy about South Asian families all looking after each

other and there is no issues for them, this has totally blown it out of the water, really, my experience over the last five weeks, because even colleagues of mine say they look after each other – well, they clearly don't any more ... it is not automatic like you would think it was. It is a stereotype ... So that means that our idea that people don't need this help is wrong; they do need this support but people don't know enough about dementia at all in the family, so they are not going for any help.'

(Alzheimer's Society facilitator interview 7, December 2014)

As this quote clearly illustrates, the learning from IPSAF helped staff reflect on their wider work. This included understanding specific needs within South Asian communities which were not met by existing services, for example, the extended family's need for better dementia-awareness, in order to support primary carers. Alzheimer's Society facilitators also felt their understanding of barriers encountered by South Asian communities when attempting to access services had improved. It is worth noting, however, that such cultural learning is an ongoing process. It is not our intention to suggest that participation in the IPSAF process equates to expertise in the dynamics of diverse South Asian communities.

Several discussed employing their improved awareness beyond IPSAF:

'I know that people from the South Asian community don't come to [our existing services] so I think perhaps to have something around a café, carers' group, for the South Asian community specifically would benefit ... I think it's that you've got to be able to adapt our existing services to be able to benefit the South Asian community.' (Alzheimer's Society facilitator interview 5, December 2014)

One Alzheimer's Society interviewee at the national level also raised the possibility of employing more minority ethnic workers who had the knowledge to work with culturally specific groups. While a more diverse workforce would clearly be of value, it is important to note that facilitators understood building links with minority ethnic communities through local organisations to bring additional benefits, and saw this as an approach they could use with other communities. Working in partnership helped build trust with community members, because, in the words of one Alzheimer's Society staff member: *'the people we recruited to do the programme would have already known this centre ... they were like our flag-bearers'* (Alzheimer's Society facilitator interview 3, December 2014). Thus, the partnership helped improve the Society's access into communities they had previously struggled to reach.

In most sites, improved access remained via the community organisation, rather than generating more direct links with local communities. However, where recruitment was carried out jointly (rather than the Society using their usual routes and the community partner focusing on more informal communication within the community), this enabled the Alzheimer's Society facilitator to strengthen their own community connections. For example, in one site, home visits explaining IPSAF to prospective participants were undertaken jointly by both partners. This strengthened trust and relationships between participants and

both organisations, and enabled Society staff to offer additional services directly to families. This tended to occur in sites where the Alzheimer's Society facilitator saw working with South Asian communities as an important element of their primary role. Thus, it may be that the ongoing benefits to the larger organisation are maximised where they are able to form a directly collaborative relationship with the BME community partner, rather than dividing tasks according to existing expertise.

Outcomes for community partners

The majority of the community partners were unequivocally positive about the experience of working in partnership with a larger, well-known organisation (with two notable exceptions, as we discuss later). This was primarily understood in terms of enhancing their ability to meet the needs of the communities they served, as expressed by one community partner:

'It was something for us to reach out but they've reached us to give this to our community and we're thankful for that.' (Community Partner interview 2, December 2014)

Community partners frequently saw IPSAF as extending what they were able to offer their community. They were keen to be involved with further dementia awareness-raising work, and other services provided by the Alzheimer's Society such as singing groups or wellbeing cafés. Community partners who had previously lacked dementia knowledge were particularly enthusiastic about their improved ability to support carers through sign-posting to services, and about developing new projects to raise awareness. Community partners (and the people they served) therefore benefited where IPSAF was understood as a first step in developing a range of more culturally appropriate services, rather than a discrete, single event.

In addition, most valued the recognition that a larger, well-connected organisation brought, and felt that working with a national organisation could open new opportunities. Thus, a partner reported that they were now being approached by other organisations for their expertise:

'Yesterday we went to television studio to do a little talk about that on British Muslim TV... we did a little talk about dementia and they wanted to know about the personal stories.'
(Community Partner interview 4, December 2014)

Similarly, most valued the opportunities to connect with other like-minded BME VCS organisations which the wider programme brought, for example, through the joint cultural competency training.

However, while the improved connections echo the Alzheimer's Society's organisational gains in terms of improved access to communities, there was less parallel in terms of knowledge-gain. In particular, there was very limited evidence of community partners gaining substantial learning around dementia (dementia education and training was not offered to partners, as discussed further below), despite some

acknowledgement from both Alzheimer's Society facilitators and community partners that limited dementia knowledge made it more difficult for community partners to co-facilitate effectively.

An equal partnership?

IPSAF evaluation evidence clearly suggests benefits to all three stakeholder groups: local communities, the Alzheimer's Society and community partners. In most cases, the community partners and the local Alzheimer's Society branches reflected very positively on the strength and value of the partnership they formed, as symbolised by plans for ongoing collaboration. In most sites, both partners were keen to either deliver IPSAF again or work together on other projects. Although not all had formed concrete plans, most facilitators described the value of the relationships they had formed, and how they might use these in the future:

'I think the bright side is that we're going to be working together in the future ... so I think it's bright. I can see something is there for us as an organisation.'

(Community Partner interview 6, December 2014)

However, in two cases (not including the organisation that chose not to co-deliver) the community partners found the experience more frustrating. Despite their desire to participate equally, they felt they were not treated as equal partners, leading them to feel their work had not been adequately valued. As one put it:

'We didn't really get appreciated ... I believe that partnerships are two-way. I believe that without us, they would have had no chance doing it.' (Community Partner interview 1, October 2014)

This sentiment was strongly echoed by another community partner, who described the extent of their contribution:

'We gave them clients, we gave them venue, and we co-facilitated, and even then, they didn't appreciate it.' (Community Partner interview 7, July 2015)

This perspective directs our attention to the working dynamics of all the partnerships. The final section of this paper therefore reflects briefly on the extent to which, in practice, the Alzheimer's Society and its community partners were able to gain *equally* from the collaboration.

The evidence from all sites suggests that a positive and equal relationship in terms of delivery planning was considered important. Good communication, joint planning and preparation were essential elements in building a good working partnership, and ultimately in the success of the process. While there was some variation at local level, the Alzheimer's Society encouraged good communication and regular meetings to plan the course practicalities and prepare for facilitation.

There was, however, a lack of partner involvement during the earlier planning stages in each locality. In terms of local branch applications to run IPSAF, even in the site where a prior working relationship existed, the community partner was not invited to help develop the application, or asked what resources they would need. Accordingly, this organisation found it frustrating that the course was not, in their opinion, properly resourced, and that they were not shown the budget in order to judge what was possible themselves.

Similarly, there was some variation regarding whether payment to community partners was considered necessary by the local Society branch, and how this was perceived by community partners. Some more established BME VCS organisations drew up contracts and charged for their time, while others contributed staff time free of charge. Some were happy to be asked to contribute without payment, because it *'fitted in with [their] role'* (community partner interview 5, December 2014), while others felt *'used'* (community partner interview 1, October 2014). This related to whether community partners saw it as a core element of their existing role (in which case payment might not be seen as necessary), or understood themselves as contributing to an Alzheimer's Society project as an additional work commitment (in some of these cases, payment was understood as an appropriate recognition of their valued contribution).

This issue relates to perceptions of the nature and value of each partner's contribution. Overall, there appeared to be broad agreement between Alzheimer's Society facilitators and community partners regarding their roles. Both sets of facilitators agreed that the community partner took the lead in recruitment, and often in making the practical 'house-keeping' arrangements as well. However, there was variation both in the degree to which the Alzheimer's Society partner also worked on recruitment, and the degree to which this function was overtly valued as skilled and important. Where community partners felt recruitment was 'left to them', this did not work well in terms of building a successful partnership. Conversely, some Alzheimer's Society facilitators explicitly valued the cultural knowledge and communication skills involved in recruitment, as here:

'I think the role of the partner has been to communicate what we're doing, the benefits of what we're doing and why we're doing it ... the positive impacts it can have on them as carers, but the wider family as well and the wider community.'

(Alzheimer's Society facilitator interview 5, December 2014)

While, in most cases, both Alzheimer's Society staff and community partners strongly appreciated what they were able to learn through the collaboration, this was not always the case:

'I wasn't entirely clear what her role was supposed to be in terms of the co-facilitation because obviously I was aware that she didn't have the dementia knowledge.' (Alzheimer's Society facilitator interview 1, December 2014)

Moreover, the value placed on knowledge shared by community partners was not always adequately communicated. For example, while Alzheimer's Society staff stressed the importance of their partners' participation in the cultural competence training as a central element in their learning, several partners said that they were already familiar with a lot of the information covered, and understood the training invitation to mean their expertise had not been acknowledged.

The structure of the training also illustrates a discrepancy in the extent to which organisational learning for each partner was facilitated. Attendance on the cultural competency training was mandatory for everyone, with the specific aim of supporting Alzheimer's Society staff in learning from community partners, as a national Society staff member described:

'It's not necessarily needed by [the community partners], but there's a lot of conversation and discussion that we want to encourage at that training so that our staff member ...is able to talk to their partner that they're going to work with, to learn from them ... how does this [concept] apply in the community that we're going to work with, and to start planning.'

(National Alzheimer's Society staff interview 1, January 2015)

This contrasts with a reluctance to embed dementia training for community partners, unless there is an ongoing benefit to the Alzheimer's Society:

'I think to have that grounding [in dementia] ... nothing would be harmful but the trouble is we have got so many CrISP facilitators in the organisation. It is costly, and there are a lot of people not using it, so I don't think they wanted to keep training up more people who aren't going to use it. So if [the co-facilitators] had the training ... it might never be used again for the Alzheimer's Society.'

(Alzheimer's Society facilitator interview 7, December 2014)

It is therefore evident that a different logic is at work in terms of knowledge transfer to and from community partner organisations. There is an apparent assumption that smaller BME VCS organisations will be willing to share their knowledge freely, but this is (organisationally, at least) perceived as a more difficult resource issue when the knowledge flow is in the other direction. While individual Alzheimer's Society staff members were most willing to share their knowledge and support their partners' learning, the evaluation evidence nonetheless suggests a marked disparity between Society cultural learning and community partner dementia learning.

Arguably, this outcome reflects a concern, on the part of the Alzheimer's Society, with protecting their position as a provider of service 'choice'. This dynamic was indicated by the concern mentioned above regarding dementia training for community partners, which *'might never be used again for the Alzheimer's Society'* (Alzheimer's Society facilitator interview 7, December 2014), and was also manifested in the issue

of ownership. At least two community partners expressed a desire to deliver IPSAF alone (in one case, feeling this would enable them to tailor it more appropriately). Similarly, one national member of Alzheimer's Society staff voiced the aspirational view that she would like to *'ideally, in the future, see South Asian organisations delivering the programme themselves, because I think that is the real empowerment'* (National Alzheimer's Society staff interview 2, January 2015). This notwithstanding, IPSAF is at present fully 'owned' by the Society as a core service (with associated implications for intellectual property rights and for attracting funding), though it has clearly been developed with input from both the Alzheimer's Society and its local BME VCS partners, input that was, in most cases, freely given. Thus, while a service new to both community partners and the Alzheimer's Society was developed through the combination of both sets of knowledge, the Alzheimer's Society's ability to position itself as a provider of 'choice' (and thus its ability to attract funding to deliver BME dementia services) was enhanced through the partnerships to a greater degree than that of the community partners. While the larger question of 'intellectual property' and the voluntary sector is beyond the scope of this article, if such property is understood to exist, it is important to recognise all contributing sources of knowledge.

Balancing this, plans for the future suggest a potential for more equal outcomes in terms of ongoing service development. Proposals for jointly-run projects included a dementia-friendly singing group, a befriending service, a South Asian specific dementia café, and co-delivering IPSAF again (in some cases, with the community partner taking a more active role). In at least 2 sites, community partner organisations were developing plans for their own projects, with the active support of the local Alzheimer's Society office. This included some dementia-themed 'open days' at a community centre, as well as a carers' support group, intended to continue support for IPSAF participants, and provide an opportunity for other carers to join.

To summarise, both the national charity and the local partners were able to offer an improved service, and both gained positive new contacts. However, control of planning and resource allocation rested with the Alzheimer's Society, and broader skills development was less equal.

Conclusion

The case of the Alzheimer's Society's Information Programme for South Asian Families supports the view that collaboration between leading national charities and smaller BME VCS organisations does have the potential to improve outcomes for marginalised communities. A good partnership was essential to the success of the IPSAF programme in each locality, with the ensuing combination of skills, knowledge and experience generating positive outcomes for participants. Community partners played a vital role in identifying and building trust with potential participants, and in ensuring the cultural appropriateness and relevance of the programme content, while the Alzheimer's Society brought recognised dementia expertise and resources. Successful partnerships had clear shared goals, personally committed facilitators from both

organisations, and a wide range of knowledge and experience, including local, cultural and dementia knowledge, excellent facilitation skills and community development experience.

The partnerships additionally delivered positive outcomes for the lead charity, both in terms of improved services and their own organisational development. A key outcome for the Alzheimer's Society was increased cultural knowledge and understanding, which could be applied to their full range of services. For the BME VCS partners, improved connections and ongoing opportunities for joint working were the primary positive outcomes. However, there is also evidence that while there were gains for both sides of the partnership, the design of the programme meant that 'knowledge transfer' flowed primarily from BME VCS organisations to the national charity, rather than vice versa. This appeared to be based on an implied expectation that meeting community needs would be a sufficient outcome for community partners, while the lead charity, through control of the programme design, was able to more effectively maximise its own structured learning. Arguably, and given the voluntary sector context described earlier, larger organisations which are more conscious of the need to embrace the expected 'choice' role, emerge from the partnership with greater gains than smaller organisations which retain a primary focus on 'voice'. Both sides of the partnership contributed to the development of a new service, which extended their existing provision (from generic dementia provision to culturally tailored provision, or from broader culturally tailored provision to dementia specific provision). Accordingly, there is a danger that, without more conscious attention to the organisational needs of BME VCS partners, the partnership may leave smaller (and thus structurally more vulnerable) organisations such as these less well placed for the future (given a competitive funding environment in which both partners need to attract ongoing support for BME health service provision).

Importantly, however, the IPSAF experience also suggests that the outcomes for *both* sides of the partnership are likely to be strongest where collaboration is more equal. For the national organisation, their opportunities to build trust with local communities are greatly improved by working *with* community partners (rather than delegating recruitment, for example). Correspondingly, the outcomes for BME VCS partners would be enhanced by building learning opportunities for both sides of the partnership equally into the programme design. The IPSAF experience further suggests that an equal and positive partnership is also more likely to encourage continued collaboration, and thus ongoing benefits for communities and organisations.

Drawing on the learning from IPSAF, equal (and thus more effective) partnerships are likely to be facilitated through shared goals (fitting the organisational aims of both partners), early involvement of both partners in planning and development, an open and collaborative approach to resources, agreement over roles and responsibilities, mutual respect for each partner's skills and knowledge (including allowing these to shape design as well as delivery), equal attention to both partners' organisational needs, good communication and detailed joint preparation. Smaller BME organisations may also benefit from alliances with similar

organisations, either formally to enable more equal collaboration with national organisations, or informally to share learning from partnership experiences. Normatively, a ‘creative commons’ approach to voluntary sector service development would seem helpful in facilitating the open sharing of knowledge – while this appears unlikely in an increasingly competitive and marketised context, it is nonetheless valid to note. The evidence presented here therefore suggests that a critical awareness of the needs of *both* organisations is likely to play a positive role in realising the potential of intra-sector partnerships to transform provision for marginalised communities.

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