

# **Promoting Inclusion and Partnership (PIP) project**

## **Final Report**



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July 2006**

## **Acknowledgements**

We would like to thank members of both the Project Working Group and the Pilot Branch Group for their invaluable advice and support throughout the duration of this project.

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### **Pilot Branches**

Barnsley branch

Bradford branch

Huddersfield branch

Hull and East Riding branch

Richmondshire branch

Sheffield branch

**Thank you to all branches in the Yorkshire Area  
that participated in the PIP project**

## **PIP Project Executive Summary**

This report provides an overview of the activities and outcomes of the Promoting Inclusion and Partnership (PIP) project, funded by Yorkshire and Humberside Regional Forum. The project ran from November 2005 until June 2006 and sought to meet a variety of objectives:

- To assess the number of people with different forms of dementia including younger people
- To establish details of services provided by branches of the Alzheimer's Society
- To establish details of other agencies providing dementia care services and existing forums and networks
- To establish gaps in services delivery and the need for future service provision and to establish opportunities for partnership working and for creating networking
- To obtain a better understanding of the black and minority ethnic (BME) communities in relation to dementia care
- To make recommendations on further work, or identify opportunities, that can help the delivery of effective services to those touch with dementia across the Yorkshire & Humberside region Alzheimer's Society

The final Report on the PIP project delivers a commentary on how each of these objectives was approached and tackled<sup>1</sup>. As well as clear outcomes and recommendations, the project has raised some 'unsolicited' but very important issues, captured within Section 6 which should be considered in future planning for the Area as well as for the Society as a whole.

Summary of Project outcomes:

1. Numbers of people with dementia in Yorkshire: PCT's were asked to provide statistics regarding people with dementia in their area. The majority of PCTs could not provide actual or estimated numbers of people with all forms of dementia in the Yorkshire Area. The PIP project estimated numbers of people with dementia in branch areas by extrapolating from credible population and prevalence data.
2. Audit of Branch services: Services provided by the 19 branches that completed the Audit form are variable. The majority of branch services are aimed at carers. The national Alzheimer's Society has benefited in terms of the lessons learned from the PIP Audit

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<sup>1</sup> See sections 1 –5 of the Report

Form in the development of audit procedures for branches throughout England, Wales and Northern Ireland.

3. A total of six branches were chosen to be pilot branches for the PIP project focusing around the key themes of partnership and/or inclusion. To this end the Yorkshire Area Office chose three focal themes: urban inclusion, rural inclusion and black and minority ethnic communities. The six branches that were chosen were selected on the basis that each was dealing with practical issues relating to one of the focal themes. As a direct result of their involvement as PIP pilot branches, two branches have benefited from successful applications for continuation funding from Regional Forum, under their 'Networking' Priority Theme. Huddersfield branch has received funding to attend meetings with organisations representing people from black and minority ethnic communities, produce articles for the local media on this work and make recommendations on future partnership working. Richmondshire branch has been funded to pilot a joint working project with other agencies to provide an activities service for people with dementia in Leyburn, to evaluate this service by consulting service users and developing future partnership working.
4. PIP project initiatives have contributed to new service development, the production of a DVD capturing users' personal experience of their journey through dementia for internal and external use<sup>2</sup>, new external partnerships with other relevant organisations, collaborative working internally and externally, and has initiated dialogue and action within branches about inclusion.
5. Inclusion of people from BME communities: People from Black and Minority Ethnic communities indicated that their knowledge of the Alzheimer's Society could be improved. Successful partnership work within the Yorkshire Area with BME groups offer new models of service provision to 'hard to reach' communities.
6. Service partnerships: It is an important objective of the Alzheimer's Society to work with other agencies to achieve its goals<sup>3</sup>. Ways that branches can learn about best practice from each other have been suggested<sup>4</sup> and the importance given to this activity needs to be very high. Inclusive partnerships may only be achievable if branches consider that the delivery of services and support may have to be much more tailored to the person with dementia and those that care for them.

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<sup>2</sup> DVD: 'My Voice' available from Yorkshire Area Office

<sup>3</sup> To be a leading authority on all aspects of living with dementia

<sup>4</sup> Section 3

## **Recommendations:**

A series of recommendations were made on improvements to future partnership and inclusion work, in specific areas of activity, within the Yorkshire Area Alzheimer's Society.

### *Audit and Information*

1. All branches to systematically record number of different service users, periodically shared with Yorkshire Area Office
2. All branches to create and maintain their own websites
3. All branches to produce regular newsletters to Society standards and maximise distribution to stakeholders

### *Internal Partnership*

1. Based on evidence of need develop services so they are provided locally and across the wider Yorkshire area
2. Consultation with branches about low level of provision of services to people with dementia and inclusion of people with dementia in branch activities

### *External Partnership*

1. Showcasing examples of good practice in partnership working by branches in Yorkshire Area
2. Local mapping of other 'partner' organisations that may have access to people with dementia and their carers and contact made with a representative. Information to be periodically shared with Yorkshire Area Office

### *Black and Minority Ethnic Communities*

1. All branches should systematically, appropriately and sensitively seek to monitor the ethnicity of service-users
2. Creation of a BME Forum for Yorkshire Area
3. Work with partners from Black and Minority Ethnic Communities to improve understanding of work done by Alzheimer's Society branches

## **Further information:**

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## **Foreword July 2006**

The opportunity to participate in the promotion of inclusion and partnership through the PIP project funded by the Yorkshire & Humberside Regional Forum has been warmly welcomed by the Alzheimer's Society. I congratulate Nicki Dyson, Area Manager for Yorkshire on taking this initiative.

As the Alzheimer's Society consolidates after a period of significant internal change, it is crucial that we seek first to understand the numbers and needs of people with dementia of all ages and ethnicity in our cities, towns and rural areas, so that we can better provide for and influence the delivery of those services that meet their needs and those of the people who care for them. That done, we then must ensure we are clear about why we deliver what we do and constantly test out the effectiveness of our work with the people who most need our support.

This Report captures evidence of the numbers of people with dementia within Yorkshire through requesting information from Primary Care Trusts (PCTs) and also through extrapolating the estimated numbers from reliable prevalence and population figures. This objective was only partially achieved since figures for people with dementia were not readily available from PCTs. This raises questions about the ability of statutory authorities, let alone voluntary organisations, to make effective strategic plans for the provision of support to people with dementia and their carers.

With the recent General Medical Council's guidance to GPs for incentives for them to monitor and record the numbers of people with dementia registered with each GP practice, there is the best opportunity yet for us to seek to influence the collection of this important information and to work with GPs to help with service support.

This project has also been timely as it has allowed us to effectively map our own service delivery via the branches in Yorkshire, all of whom cooperated willingly in the audit. The process of the mapping audit was shaped with the help of Maria Tuck who is responsible for the Society wide mapping project and the learning from this audit will help with designing this bigger piece of work.

The Report demonstrates the scope of the activities that have accompanied the PIP project and the outcomes that have flowed from it. Of particular importance has been the capturing of the personal experiences of people directly affected by dementia and this

process is described in Section 4. Of particular benefit too are the outcomes described in Section 7 that, while directly related to the PIP project itself, nevertheless represents evidence of the impact that undertaking the work has had beyond the original objectives.

The recommendations at the end of the Report will form a vital ingredient for our future planning but as well as these, the journey through the project has raised some important questions for us to consider around the areas of Inclusion and Partnership. These questions centre on the unclear picture of our potential and actual service users, how we communicate both internally and externally, the services we deliver for people with dementia and carers and, finally, the important question of partnership working. Section 6 discusses all of these points and it makes for thought-provoking and interesting reading for us as we embark on the future direction and planning for the Society.

There is no question that the pilot branches in Yorkshire who willingly participated, demonstrated that staff members are enthusiastic about developing their services in line with the principles of partnership and inclusion. However, for the Alzheimer's Society to truly absorb these principles there are some barriers to overcome<sup>5</sup> as we work towards ensuring a world where people with dementia and those who care for them have their rights recognised and their needs fully met; a world where they can fully contribute to family and community life and where they can live with dignity, free from discrimination.

This Project has been a critical piece of work and underlines the importance to us of ensuring all that we do is based on a sound knowledge of the evidence. I am immensely grateful to Nicki and all of the members of the working group, to David Reid who guided us and who wrote up this Report and in particular, for the hard work and commitment of the volunteers and staff within the Yorkshire area.

I warmly recommend this Report to the wider Alzheimer's Society.

Maggie Williams  
**Director North Region**

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<sup>5</sup> See Section 6

## **Introduction**

This report provides an overview of the activities and outcomes of the Promoting Inclusion and Partnership (PIP) project. The PIP project has been funded by *Yorkshire and Humberside Regional Forum*. The Alzheimer's Society obtained funding for the project and contracted this work to the University of Sheffield. The activities of the PIP project have been undertaken between November 2005 and June 2006.

The PIP project has sought to meet a variety of objectives in the funded period (see Box 1).

### *Box 1: Objectives of the Promoting Inclusion and Partnership (PIP) project*

- 1) Assess the number of people with different forms of dementia including younger people
- 2) Establish details of services provided by branches of the Alzheimer's Society
- 3) Establish details of other agencies providing dementia care services and existing forums and networks
- 4) Establish gaps in services delivery and need for future service provision and establish opportunities for partnership working and for creating networking
- 5) Obtain a better understanding of the black and minority ethnic (BME) communities in relation to dementia care
- 6) Make recommendations on further work, or identify opportunities, that can help the delivery of effective services to those touched with dementia across the Yorkshire & Humberside region and national Alzheimer's Society

This Final Report on the PIP project is structured so that a commentary is provided on how each of these objectives was approached and tackled (Sections 1-6). Some of the objectives outlined in Box 1 were not pursued through specific research activities or branch initiatives but, instead, were tackled in a number of activities or initiatives.

Section 1 of this Final Report describes both attempts to obtain and attempts to estimate the numbers of people with different forms of dementia currently living in the Yorkshire Area.

Section 2 consists of a detailed description of the responses from branches of the Alzheimer's Society in the Yorkshire Area to an Audit Form designed to capture a snapshot of their branch service activities.

Section 3 provides an overview of research, practical initiatives undertaken and the outcomes of this activity with 6 PIP 'pilot' branches. These branches were chosen for specific PIP activities which were all targeted at either promoting improvements in the degree to which branches were 'inclusive' or promoting the amount of partnership working branches were undertaking with other relevant organisations.

Section 4 describes the development of a DVD including people with dementia and carers.

Section 5 includes reflections on what was learnt about the distinctive dementia care needs of people from black and minority ethnic communities.

Section 6 highlights additional outcomes that have arisen as a result of the PIP project.

In Section 7 there is a discussion of the major issues that arose during the course of the project in relation to partnership and inclusion.

Section 8 provides the recommendations that are made to the Alzheimer's Society Yorkshire Area Office on the basis of the findings of the PIP project.

## **Section 1: Numbers of people with dementia in the Yorkshire Area**

In order that the Alzheimer's Society Yorkshire Area office, and the branches in the Area that it supports, are able to gauge the extent to which they are meeting the needs of people with dementia it is important that they have accurate figures of the numbers of people with dementia in their respective areas. In addition, it is also important that the Alzheimer's Society, an organisation that seeks to offer support to people with all forms of dementia, has accurate figures for the numbers of people with all forms of dementia. In response to this organisational need one of the PIP project objectives was to seek to discover this information. Two strategies were used to try to do this: requesting information from Primary Care Trusts (PCTs) and extrapolation of estimated numbers from reliable prevalence and population figures.

### *Information from PCTs*

The first strategy employed here was to approach 30 PCTs in Yorkshire and North Lincolnshire to ask them for their own recorded figures for the numbers of people with dementia. Letters were sent to the information officers or Chief Executives of all PCTs in January 2006. Responses were received from nearly all PCTs to confirm that this request had been passed on to the relevant department. However, only three PCTs provided an estimate of the numbers for people with dementia. These were the three Sheffield PCTs. Others responded that they did not have or did not collect this information. Others asked to be informed if it was found that PCTs other than their own were able to provide this information.

This disappointing response suggests that PCTs are currently an unsuitable source of information for estimated numbers of people with dementia. During the course of the PIP project an alternative source of this information, in the future, was heralded in new guidance given to GPs by the General Medical Council (GMC) in February 2006. This is a new initiative to encourage GPs to keep a register of patients diagnosed with dementia. It is encouragement and not a requirement and the guidance appears in the GMS Contract Revision document in relation to Quality Outcome Framework (QOF) indicators. The guidance can be found by visiting the following website:

[http://www.bma.org.uk/ap.nsf/AttachmentsByTitle/PDFGMScontractrevisionsFeb2006/\\$FILE/GMScontractRevisionsFeb2006.pdf](http://www.bma.org.uk/ap.nsf/AttachmentsByTitle/PDFGMScontractrevisionsFeb2006/$FILE/GMScontractRevisionsFeb2006.pdf)

According to the Yorkshire and Humberside Public Health Observatory dementia prevalence data collated by GPs will eventually be published via 'QPID' – Quality, Prevalence and Indicator Database – which makes available QOF data to the general public on the HSCIC website - the link to currently released data is:

<http://www.ic.nhs.uk/services/qof/data/>

The next release of data will occur around August this year for the 2005/06 dataset. Dementia prevalence will be collected in practices from April 2006 and will become part of the 2006/07 dataset. According to the Yorkshire and Humberside Public Health Observatory access to this information will be possible from around August 2007. This initiative offers the Alzheimer's Society in the Yorkshire Area, and nationally, a future source of dementia prevalence information. However, the GMC Contract Revision document does not encourage GPs to collect information about the sub-types of dementia and this may be a limitation in terms of the Alzheimer's Society's needs. It is also worth noting that any future publicly accessible information about the numbers of people with dementia relies on GPs to collect this at Practice level and the extent to which GPs are committed to doing so is as yet unknown.

#### *Estimating prevalence of dementia*

The Alzheimer's Society currently estimates the number of people with dementia in areas of England, Wales and Northern Ireland by drawing upon estimated resident figures and applying prevalence rates from the research literature. The resident figures are reported to be obtained from The Office for National Statistics who, in turn, are informed by Strategic Health Authorities, PCTs, Local Health Boards and NHS Boards. It was not within the scope of the PIP project to scrutinise either the validity of these figures or the calculations of estimated numbers by extrapolation of given prevalence rates. The dementia prevalence rates used by the Alzheimer's Society are presented in Table 1.1.

A similar extrapolation exercise was undertaken in the PIP project as the second strategy used to estimate the numbers of people with dementia in the Yorkshire Area. A heavily cited academic paper reporting the combined prevalence rates from a number of comparable European dementia prevalence studies was used (Hofman *et al* 1991). The combined prevalence rates reported by Hofman *et al* (1991) are shown in Table 1.2.

Table 1.1: Alzheimer's Society dementia prevalence rates

Age	Prevalence
40-64	1 in 1,000
65-69	1 in 50
70-80	1 in 20
80 plus	1 in 5

Source: Alzheimer's Society Yorkshire Area Office

Table 1.2: Dementia prevalence rates used in the PIP project

Age (years)	Prevalence (% of population)
30-59	0.1
60-64	1
65-69	1.4
70-74	4.1
75-79	5.7
80-84	13
85-89	21.6
90 plus	33.45

Source: Hofman *et al* (1991)

In order to estimate the numbers of people with dementia, population data for appropriate areas of the Alzheimer's Society Yorkshire Area was obtained from UK Census data on the Office of National Statistics website (see Appendix 1). The prevalence rates suggested by Hofman *et al* (1991) were applied to this population data to calculate numbers of people with all forms of dementia in branch areas of the Yorkshire Area (see Appendix 2). The total number of people with dementia was estimated to be 64,151 and the total number of younger people with dementia (i.e. 30-59 years old) was estimated to be 2,034.

The figures given for each branch are for geographical areas which were judged to approximate with branch areas. As such the figures should be treated with caution as these approximations may either over- or under-estimate the actual numbers of people with dementia in each 'actual' branch area. In addition, if the branch estimates for numbers of people with dementia are summed the total figure does not correspond with the total estimate for Yorkshire and Humberside.

This is because some population figures given by the Office for National Statistics (e.g. West Yorkshire County; North Yorkshire County) cannot be assigned to a specific branch of the Alzheimer's Society.

An attempt was made to compare the estimated numbers of people with dementia in each branch area calculated in the PIP project with the estimated numbers calculated by the Alzheimer's Society (Table 1.3). This comparison demonstrates that in most areas there is very little difference between the two methods of calculation. However, the estimated numbers of people with dementia in Bradford, the East Riding of Yorkshire and in Kirklees were appreciably higher under the PIP method. This variation may be due to differences in the population figures used but more research is needed to confirm this suggestion and/or identify other factors.

The second element of the attempt to estimate numbers of people with dementia was to try to estimate numbers of people with different forms of dementia. This task was undertaken utilising Alzheimer's Society figures for the breakdown of the category of dementia into people with:

- Alzheimer's disease (PWAD) (55%),
- Vascular dementia (PWVD) (20%),
- Lewy Bodys (PWDLB) (15%),
- Frontal-lobe dementia (PWFLD) (5%)
- People with other dementias (PWOD) (5%)

These calculations were achieved by applying the percentages contained in the breakdown of dementia type to the estimated numbers for all people with dementia in each branch earlier (Appendix 2). As well as indicating the breakdown of dementia type for each branch area (Table 1.4) these calculations also allow an estimate of the total numbers of people with different forms of dementia in Yorkshire (Table 1.5).

Table 1.3: Comparison of estimated numbers of people with dementia

<i>Location</i>	<i>Alzheimer's Society estimated total PWD (A)</i>	<i>PIP project estimated total PWD (B)</i>		<i>Difference between estimates A and B (%)</i>
Barnsley	2817	2712		-4%
Bradford	3798	5456		44%
Calderdale	2573	2505		-3%
Craven	3254	925	3215	-1%
Harrogate		2290		
Doncaster	3636	3369		-8%
East Riding of Yorkshire	2449	4592		87%
Hambleton	1580	1158	1733	10%
Richmondshire		575		
Huddersfield	2786	*		-
Hull	2979	2893		-3%
North Kirklees	1990	4649**		134%
Leeds	9171	8953		-2%
Rotherham	3110	2983		-4%
Scarborough	2838	1928	2777	-2%
Ryedale		849		
Selby	3692	900	3391	-9%
York		2491		
Sheffield	7211	6986		3%
Wakefield	3889	3725		-4%
Yorkshire and Humberside	-	64151		-

\*UK Census 2001 data for Yorkshire did not include discrete data for Huddersfield

\*\*Figure is for Kirklees as a whole

*Table 1.4. Estimated numbers of people with different types of dementia by nominal branch area*

Location	Type of dementia					Total PWD
	PWAD	PWVD	PWDLB	PWFLD	PWOD	
Barnsley	1435	522	391	130	130	2610
Bradford	3001	1091	818	273	273	5456
Calderdale	1378	501	376	125	125	2505
Craven	509	185	139	46	46	925
Doncaster	1853	674	505	168	168	3369
East Riding of Yorkshire	2526	918	689	230	230	4592
Hambleton	637	232	174	58	58	1158
Harrogate	1259	458	343	114	114	2290
Huddersfield*	-	-	-	-	-	-
Hull	1590	579	434	145	145	2893
Kirklees	2557	930	697	232	232	4649
Leeds	4925	1790	1343	448	448	8953
Richmondshire	316	115	86	29	29	575
Rotherham	1640	597	447	149	149	2983
Ryedale	467	170	127	42	42	849
Scarborough	1060	386	289	96	96	1928
Selby	495	180	135	45	45	900
Sheffield	3842	1397	1048	349	349	6986
Wakefield	2049	745	559	186	186	3725
York	1370	498	373	125	125	2491
Total Yorkshire and Humberside	35283	12830	9622	3207	3207	64151

\*It was not possible to access comparable data for Huddersfield from UK Census 2001

*Table 1.5. Total numbers of people with different forms of dementia in Yorkshire*

Alzheimer's disease	35,283
Vascular dementia	12,830
Lewy Bodys dementia	9,622
Frontal-lobe dementia	3,207
Other forms of dementia	3,209
Total of estimated people with dementia in Yorkshire Area	64,151

The future use of these estimates to the Alzheimer's Society Yorkshire Area Office is beyond the remit of the PIP project. However, they do provide a useful source of information to compare with the numbers of people with different forms of dementia known to branches.

### *Summary*

This PIP project objective was only partially achieved, in the sense that figures for people with forms of dementia were not readily available from PCTs. However, this is a finding in itself and raises questions about the ability of statutory authorities, let alone voluntary organisations, to make effective strategic plans for the provision of support to people with dementia and their carers. Yet, towards the end of the PIP project it was announced via GMC guidance to GPs that incentives would now be in place to encourage GPs to monitor and record numbers of people with dementia registered with each GP practice. This is guidance and does not imply the collection of this information is compulsory. However, what it will mean is that from April 2007 the information collated by GPs will be available to the public via a website.

### **Reference:**

Hofman, A., Rocca, W. A., Brayne, C., Breteler, M. M. B., Clarke, M., Cooper, B., Copeland, J. R. M., Dartigues, J. F., Da Silva Droux, A, Hagnell, O, Heeren, T. J., Engedal, K., Jonker, C., Lindesay, J., Lobo, A., Mann, A. H., Molsa, P. K., Morgan, K., O'Connor, D. W., Sulkava, R., Kay, D. W. K., Amaducci, L. (1991) The Prevalence of Dementia in Europe: A Collaborative Study of 1980-1990 Findings. *International Journal of Epidemiology*, 20 (3): 736-748.

## **Section 2: An audit of branch service activities**

The rationale for creating a branch service Audit Form was two fold. Firstly, the form was intended to create a snap-shot of branch service activities across the Alzheimer's Society Yorkshire Area. By asking each branch to report on standardised activities, there was an opportunity to explore the extent to which branches provide similar services to people with dementia, their carers and care professionals. While the Yorkshire Area Office had a reasonable record of these activities the circulation of the Audit Form was the first systematic attempt to gather service activity information amongst branches in the Yorkshire Area. The second aspect of the rationale for the Audit Form was also aimed at improving the area offices understanding of branch activities but, specifically, in the key area of actual or potential links with 'partnership' organisations. In asking branches to describe these links the Yorkshire Area office was seeking to enhance the transparency of branch networks with other organisations and, in so doing, recognise opportunities for consolidating and or initiating joint approaches to the provision of support to people with dementia, their carers and care professionals. A key aim in this area was to identify examples of best practice or potential circumstances which might enhance the extent to which branches are inclusive of stakeholders from all sectors of the local (branch area) communities.

### *Developing the Audit Form*

Working with the Project Working Group and later with pilot branch managers, an Audit Form was drafted and revised prior to circulation amongst branches in the Yorkshire Area. The first draft of the Audit Form was completed in December 2005. Alongside this work, there were discussions with Maria Tuck about the definition of service activities. It was acknowledged, during the drafting of the Audit Form, that different branches used different labels or categories to describe the services they provided. In addition, it was noted that some service activities were 'ambiguous', in the sense that were persuasive arguments for viewing an activity under different categories. One benefit of having Maria Tuck as a member of the Project Steering Group was that she was then undertaking work for the National Office on the development of standardised service activity audit categories. Thus, an appendix of service activity definitions was created to accompany the PIP Audit Form which was consistent with the definitions developed by Maria Tuck.

The draft Audit Form and appendix was piloted with Sheffield branch in January 2006. Feedback from Sheffield branch's manager, Judith Gregory, was invaluable in revising the document prior to circulation. Judith provided evidence that both the wording of some sections and the structure of the document as a whole could be improved to aid the form's completion.

#### *Circulating the Audit Form*

The revised, Final Draft of the PIP Audit Form and Service Activity appendix was circulated by Yorkshire Area Office via Service Managers. The majority of branches received these documents via email. The decision to ask service managers to take responsibility for circulating the documents was made in the Project Steering Group. It was felt that this was the most appropriate strategy because service managers would be available to offer support to branches that encountered difficulties completing the form. The documents were circulated to branches at the end of January 2006 with a request for them to be completed and returned to David Reid by February 15<sup>th</sup>.

#### *Difficulties with the Audit Form*

There were different approaches taken by the branches to completing the Audit Form. Some branches chose to enter their responses directly onto the computer version of the document; others printed out the form and then completed the form in long-hand. There were some reported difficulties with one aspect of the form, that was, how some of the answer boxes "moved" when typed into by respondents. This technical problem had not been foreseen as it was presumed that branches would print out the forms prior to completion. The use of a tailored questionnaire software package, with a provision for sections to expand to fit responses, would have prevented this difficulty from occurring.

The other reported problems with completion of the form were associated with i) availability of necessary information to complete sections fully and ii) ongoing service activity definition queries. The reasons for branches experiencing the first set of problems cannot be given as no explanation was forthcoming from branches that did not complete sections. In addition it is not possible to evaluate, as no reference material/ "master-copy" of existing branch service activities exists, to judge the accuracy with which branch representatives used the Audit Form to state the actual service activities undertaken by each branch.

The second set of problems was revealed in feedback received from a small number of branches, usually in telephone conversations, but also via Yorkshire Area Office staff who are in regular contact with branches. These problems of knowing how to account for certain service activities should have been alleviated by the service activity definitions appendix. None of the small number of branches, who reported experiencing difficulties in this area, were nominated pilot branches. For this reason, these branches would not have had an opportunity to see the forms beforehand and, perhaps at that stage, raised questions and obtained guidance.

### *Completion of the Audit Form*

By mid June 2006, 19 branches had completed and returned their forms (17 branches had responded by April 2006). The reason for slow completion of the Audit Form by two branches was said by the Yorkshire Area Office to be due to limited resources at branches. The completed Audit Forms contained both 'closed' and 'open-ended' question responses about branch service activities. The following section represents a comparative analysis of branch service activities. Its primary aim is to demonstrate the range of activities currently provided, and the degree to which branches collect basic information about service-users.

## **Results**

The Audit Form was completed by staff at 19 branches of the Alzheimer's Society in the Yorkshire Area (see Box 2.1).

### *Box 2.1: Who completed the Audit Form?*

<i>Designation</i>	<i>Number</i>
Branch Managers	8
Administrators	2
Branch secretaries	2
Family Support Workers	2
Befriending scheme coordinator	1
Chair of branch committee	1
Service Manager	1
Branch Development Manager	1

Not stated	1
<i>Total</i>	19

### **Branch websites**

A total of 8 branches stated that they had a website while 11 said they did not. Of the 8 branches with websites, two were launched as recently as 2005, one was launched in 2003, two were launched in 2002 and three were launched in 2001 (See Box 2.2).

#### *Box 2.2.: Summary of branch website activities*

- 8 of 19 branches had websites
- Only 3 branches held information on number of 'hits'
- Number of 'hits' ranged from 250-4464
- 7 branches had updated their websites in the last year

Of the 8 branches with websites only three gave figures for the number of people who had visited the websites since they were launched. Taken together, the number of 'hits' for these branch websites ranged from 250-4464. However, a note of caution is required here as some branches reported hits in the year prior to the audit and others reported hits since the website had been started and this was sometimes longer than a year.

Four of the branches had developed their websites using branch funds and two branches had been funded to do so with specific grants (i.e. local authority; National Lottery Community Fund). One branch had been funded by the national Alzheimer's Society while the remaining branch reported having had no sources of funding to pay for their website development.

Website development had been undertaken by a variety of personnel across the eight branches. At three branches this work had been undertaken by paid staff and at a fourth by the branch coordinator and a volunteer. At other branches website development had been undertaken by national office (n=1), a volunteer (n=1), and by a final year student (presumably at University or college) on placement. Of the 8

branches with a website, seven had updated their website in the last year while one branch had not updated theirs since mid-2001.

### ***Newsletter***

Fifteen of the nineteen branches reported publishing a branch newsletter (see Box 2.3).

#### *Box 2.3: Summary of branch newsletter activities*

- 15 out of 19 branches produce newsletters
- 7 branches had published a newsletter for 10 years or more
- Most common for newsletter to be published 4 times a year (n=7)
- Number of newsletter recipients ranged from 90-1916
- Average number of newsletter recipients per branch was 285

Seven of these branches had published a newsletter for ten years or more (one had had a newsletter for 20 years). One branch had started a newsletter this year. Of those fifteen branches with a newsletter it was most common for the newsletter to be distributed four times a year (n=7). It was less common for branches to distribute newsletters three times a year (n=3) or 6 times a year (n=3) or, finally, twice a year (n=2).

All branches with a newsletter provided figures for the number of newsletters sent out the last time it was produced. The number of recipients of newsletters per branch ranged from 90-1916 and the mean number of newsletter recipients per branch was 285 individuals or organisations (this was not specified in the Audit Form). The sources of funding for newsletter costs varied branch by branch. Some branches said that the newsletter was paid for entirely out of branch funds, were included in an overall contract agreement or came from donations (n=7). Some respondents stated that the newsletter was part paid for by general funds and part paid for by specific grants (n=6). A smaller number cited specific 'ring-fenced' donations (n=1) or did not state how the newsletter was paid for (n=1).

### ***Telephone Support and Advice (TSA)***

A total of 18 branches reported providing telephone support and advice (TSA) (see Box 2.4).

*Box 2.4: Summary of TSA activities*

- 18 out of 19 branches offered TSA
- Most common for TSA to be provided entirely by paid staff (n=13)
- 16 branches recorded 'first contact' with people with dementia and carers
- 5 branches monitored the ethnicity of people contacting the branch
- Number of carers in contact with branches for TSA in October 2005 ranged from 3-195 (average: 57 carers per branch)
- Number of people with dementia in contact with branches for TSA in October 2005 ranged from 0-14 (average: 2 people with dementia per branch)
- Number of care professionals in contact with branches for TSA in October 2005 ranged from 0-51 (average: 9 care professionals per branch)
- Number of 'others' in contact with branches for TSA in October 2005 ranged from 0-110 (average: 21 'others' per branch)
- A total of 448 hours TSA offered by all branches each week, an average of 32 hours TSA per week per branch

It was most common for TSA to be provided entirely by paid staff (n=11) followed by that provided entirely by voluntary staff (n=3) or a mixture of paid and volunteer staff (n=2). Where TSA was provided entirely by paid staff the number of staff involved ranged from 1-9. Where volunteers were entirely responsible for TSA the number of people involved ranged from 1-3. Where a mix of paid and voluntary staff provided TSA the ratio of paid staff to volunteers ranged from 1:1 to 4:2.

A total of 16 branches stated that they kept a record of when people with dementia and their carers contacted the branch for the first time and two branches did not. One branch did not complete this question. Sixteen branches provided information about whether or not they monitored the ethnicity of people contacting the branches. The overwhelming majority did not (n=12) while a small proportion did collect this information (n=5).

Thirteen of the sixteen branches who offered TSA were able to provide figures for the number of carers who had been provided with TSA in October 2005. The numbers of carers in contact ranged from 3-195, with a total of 735 carers being reported to have received TSA from branches in the Alzheimer's Society Yorkshire Area. The average number of carers provided with TSA per branch in October 2005 was 57 people.

Thirteen branches were also able to provide figures for the number of people with dementia who had been provided with TSA in October 2005. The numbers ranged from 0-14, with a total of 27 people with dementia being reported to have received TSA from branches in the Yorkshire Area. Six branches reported that no people with dementia had received this kind of support. The average number of people with dementia with TSA support from a branch in October 2005 was two people.

Twelve branches provided figures for the number of care professionals who were provided with TSA in October 2005. The numbers ranged from 0-51 people, with four branches stating that they had not provided any TSA to care professionals in this period. A total of 119 care professionals were reported to have received TSA in this period. An average figure of nine care professionals were provided with TSA support by each branch in October 2005.

Twelve branches provided figures for the number of 'others' (though these were not specified) who were provided with TSA in October 2005. The numbers ranged from 0-110, with six branches stating they had not provided any TSA to 'others' in this period. A total of 258 others were reported to have received TSA in this period. An average of 21 'others' were provided with TSA support by a branch in October 2005.

Branches were asked to specify the sources of funding they used to pay for TSA services and fourteen branches supplied this information. Some stated that funding came from branch funds (n=3) or from specific grants (n=3: social services (n=2); Big Lottery (n=1)). Some branches cited a combination of contract funds and branch funds (n=4) while others cited funds from donations and or fundraising (n=4).

Fourteen branches provided information about the hours of the week TSA was available. The hours ranged from 6-40 hours a week, with a total of 448 hours TSA offered by branches each week. A total of eleven branches offered TSA support each day of the week with a further two offering TSA four days a week. On average, each branch was offering 32 hours TSA per week.

### ***Support and Advice Helpline (SAH)***

Branches were asked whether or not they had a dedicated Support and Advice Helpline (SAH) (see Box 2.5).

#### ***Box 2.5: Summary of SAH activities***

- 7 out of 19 branches offered SAH
- 5 branches provided information about numbers of service users in October 2005
- The total number of carers contacting branch SAHs was 104, an average of 21 carers per branch
- The total number of people with dementia contacting branch SAHs was 34, an average of 7 people with dementia per branch
- The total number of care professionals contacting branch SAHs was 55, an average of 8 care professionals per branch
- Branches offered at total of 124 hours SAH per week, an average of 41 hours per week per branch

Seven branches of the 19 who returned the Audit Form stated that they did offer a SAH. Of these seven branches, the staff members who were typically involved in the provision of the SAH varied. At two branches the SAH was staffed entirely by

paid staff (range 2-5 paid staff). At three branches the SAH was staffed entirely by volunteers (range: 1-3 volunteers) and at two branches it was both paid staff and volunteers who provided this form of support (range in ratio of paid staff to volunteers: 2:1-2:2).

Of the seven branches providing a SAH only 5 were able to provide figures for the number of carers who had used this service in October 2005. The numbers ranged from 3-60 and the total number of carers contacting branch helplines was 104. The average number of carers who contacted a SAH in this time period was 21. Of the seven branches providing a helpline only 5 were able to provide figures for the number of people with dementia who had used this service in October 2005. The numbers ranged from 0-20 although three branches reported no contact from people with dementia.

The total number of people with dementia contacting branch helplines was 34. The average number of people with dementia contacting a SAH was 7 per branch. Of the 7 branches providing a helpline three reported receiving no calls from care professionals. The numbers ranged from 0-30 care professionals and the total number of care professionals contacting SAHs was 55. The average number of care professionals contacting each SAH was 8.

Six of the seven branches offering a SAH supplied details of how these services were funded. Half of these branches cited donations and fundraising (n=3) and the others cited either a mixture of contract and branch funding (n=2) or specific grant funding (n=1).

Four of the seven branches offering a SAH gave specific details of the times when this service was available. Three branches provided a service from Monday to Friday while the other offered a SAH from Monday to Thursday. The hours the SAH was available during the week ranged from 6-48. The total availability of SAH was 124 hours per week and the average time that the SAH was available at the four branches was 41 hours per week.

### ***Information, Support and Advice (ISA)***

Fifteen of the seventeen branches stated that they provided ISA (see Box 2.6).

*Box 2.6: Summary of ISA activities*

- 15 out of 19 branches offered ISA
- 13 branches provided information about numbers of service users in October 2005
- The total number of carers contacting branches for ISA was 446, an average of 34 carers per branch
- The total number of care professionals contacting branches for ISA was 250, an average of 19 care professionals per branch
- Branches offered a total of 368 hours ISA per week, an average of 28 hours per week per branch

The ISA service was provided by either paid staff members, volunteers or a combination of both. Nine ISA services were provided entirely by paid staff and these ranged from 2-7 paid staff. Three ISA services were provided by a combination of paid and volunteer staff (range in ratio of paid to volunteer staff: 2:5-4:2). One service was provided entirely by volunteer staff. In two services it was not clear which staff provided ISA services.

13 of the 15 branches offering ISA provided information about the number of carers who contacted the branch in October 2005. The reported numbers ranged from 0-208 carers. The total number of carers in contact with Yorkshire branches for ISA was 446 with the average number in contact per branch was 34. Of those branches that offered ISA, there was a wide range in the numbers of care professionals in contact for this service (0-192) during October 2005. The total number of care professionals who contacted all branches was 250. The average number of care professionals contacting each branch was 19.

Three branches said that some 'other' people (i.e. not carers, people with dementia or care professionals) contacted them for ISA. The range in the numbers of others in contact with these three branches ranged from 3-94. It was not clear who these 'others' were.

The sources of funding used to pay for ISA varied from branch to branch. At six branches ISA was paid for through a mixture of grants or contracts plus branch

funds. At a further five branches ISA was paid for through donations and or fundraising – or general funds. At two branches ISA was paid for by direct contracts.

Of the 15 branches providing ISA, 14 provided information about hours of the week ISA was available. Ten provided ISA five days a week and two offered this form of support Monday to Thursday. The range of times ISA was available varied from 0.5-48 hours per week. The average amount of time ISA was available was 28 hours per week and the total ISA provided in a week by the branches was 368 hours.

### ***Lending library***

Eleven branches offered a lending library (see Box 2.7).

#### *Box 2.7: Summary of Lending Library activities*

- 11 out of 19 branches offered a Lending Library
- In October 2005 the total number of people contacting branches to use their Lending Libraries was 16, an average of 1 person per branch
- 9 branches offered access to their libraries Monday to Friday
- Branches offered at total of 347.5 hours access to their Lending Libraries per week, an average of 32 hours per week per branch

In October 2005 the numbers of people contacting branches to use their libraries ranged from 0-6 people. The total number of people contacting branches to use their lending libraries in October 2005 was 16. Three branches stated that their funding for the costs of the lending library were met by branch funds and donations while five branches met these costs through a combination of grants/contract funding plus branch funds. Other sources of funding were exclusively contract funding or grant funding (n=2). One branch did not provide funding information.

Nine branches offered access to their lending libraries Monday to Friday while two offered this service Monday to Thursday. One branch reported that its library was

available two mornings a week. The hours of availability ranged from 6-40 hours. Branches offered an average of 32 hours a week access to the libraries and the total hours lending libraries were available amongst the branches was 347.5 hours.

### ***Drop-in service***

Eight branches stated that they offered a Drop-in service (see Box 2.8).

#### *Box 2.8.: Summary of Drop-in activities*

- 8 out of 19 branches offered a Drop-in service
- Drop-in services are provided by a mixture of paid and volunteer staff
- In October 2005 the total number of carers who used branch Drop-in services was 91, an average of 8 carers per branch
- The total number of people with dementia who used branch Drop-in services was 26, an average of 2 people with dementia per branch
- The total number of carers and people with dementia who jointly used branch Drop-in services was 169, an average of 21 carers and people with dementia per branch
- The total number of 'others' who used branch Drop-in services was 100, an average of 12 'others' per branch
- Branches offered a weekly total of 45.5 hours of Drop-in services, an average of 6 hours per week per branch

These services were provided by a mixture of paid and volunteer staff. Four branches used both paid and volunteer staff and the ratio of paid to volunteer staff ranged from 2:3 to 4:1. Three services were staffed entirely by volunteers, ranging from 1-5 volunteers. One branch's Drop-in service was provided by a single paid member of staff. However, these figures may underestimate the number of volunteer staff in the provision of Drop-in services as responses to the Audit Form did not always specify numbers precisely. The numbers of carers using branch Drop-in services ranged from 3-37. The total number of carers using Drop-in services during October 2005 was 91 and the average number per branch was 8 carers.

A smaller number of people with dementia used Drop-in services in this month. The numbers ranged from 0-19 but only three branches reported any people with dementia using Drop-in service alone (range: 2-19). A total of 26 people with dementia used Drop-in services during this month, an average of two per branch. However, three branches stated that carers and people with dementia had used the Drop-in service together (range: 2-140) while four branches reported no joint visits (one branch did not complete this question). A total of 169 people with dementia and their carers visited Drop-in service in October 2005, an average of 21 per branch. In addition, four branches said that their Drop-in service was used by 'others'. The numbers of these people attending ranged from 5-40 and the total number of these people using this type of service was one hundred, or an average of twelve people per branch. Four of the eight branches had at least part of their Drop-in service located at the branch offices. Two of these branches also provided services elsewhere (a local hotel and a local café). Of the four remaining branches, two held their Drop-in services at community centres while one provided Drop-in at a local pub. Of concern was the branch that reported that it was not able to continue providing a Drop-in service as it had no premises.

Three branches reported that a single grant source was used to pay for the costs of providing a Drop-in service while a further three branches cited donations or branch funds as paying for this service. The sources of funding used by the other two branches were a combination of grant and contract funding (n=1) and a grant plus branch funds (n=1). Drop-in services varied in their availability, ranging from 0.5-21 hours per week. The total weekly number of hours of Drop-in services provided by branches was 45.5 and the average duration of this service per branch was 6 hours.

### ***Training for carers***

Nine branches reported providing training for carers (see Box 2.9).

#### *Box 2.9: Summary of training for carers activities*

- 9 out of 19 branches offered training for carers
- Most frequently provided by single paid worker (n=4)
- 8 branches provided information about the numbers of carers who had attended training in 2005

- The total number of carers attending branch training in 2005 was 207, an average of 26 carers per branch
- In 2005 Yorkshire Area branches provided 82 training courses for carers, an average of 10 courses per branch

This service was most frequently provided by a single paid member of staff working alone (n=4). In other branches training for carers was provided by more than one paid worker (i.e. 3) (n=1), a mixture of paid staff and volunteers (n=3; range in ratio: 1:4-5:1) or by volunteers only (n=1). Eight branches responded with information about how many carers had attended training during 2005. The numbers ranged from 5-80 and the total number of carers attending training at all branches in 2005 was 207, an average of 26 carers per branch. Three branches stated that the cost of providing this training came exclusively from grants while a further one branch indicated that this service was provided as part of a contract. Three branches said their funding came from a mixture of contract or a grant plus branch funds and one branch did not provide this information.

During 2005 the range in number of training courses for carers offered by branches was 1-36 with a total of 82 provided by all branches. This is an average of 10 courses per branch. One branch did not provide this information.

### ***Training for people with dementia***

Two branches stated that they provided training for people with dementia (see Box 2.10).

#### ***Box 2.10: Summary of training for people with dementia activities***

- 2 out of 19 branches offered training for people with dementia
- 1 branch provided information about the numbers of people with dementia who had attended training in 2005
- The number of people with dementia who had attended training at this branch was 12.

At one branch this was provided by one paid worker while at the other it was provided by two paid workers and a volunteer. Only one branch provided

information about the number of people with dementia who had attended training in 2005 (i.e. twelve people) and this branch had held one training course in 2005. Similarly, one branch specified the source of funding for this service, general funds plus a research project grant.

### ***Training for care professionals***

Eight branches stated that they provided training for care professionals (Box 2.11).

#### *Box 2.11: Summary of training for care professionals activities*

- 8 out of 19 branches offered training for care professionals
- Most frequently provided by paid staff only (n=5)
- 6 branches provided information about the numbers of care professionals who had attended training in 2005
- The total number of care professionals attending branch training in 2005 was 484, an average of 60 care professionals per branch
- In 2005 Yorkshire Area branches provided 27 training courses for care professionals, an average of 5 courses per branch

The majority of these training sessions were provided by paid staff only (n=5; range: 1-6) while the remainder were provided by a mixture of paid and volunteer staff (n=3; range in ratio of paid to volunteer staff: 1:1-2:1). Six branches provided information about the number of training courses they held during 2005. These ranged from 1-13 and the total number of courses held by all branches was 27. During 2005 it was reported that a total of 484 care professionals attended training at the eight branches that provided this information. The numbers attending at each branch during this year ranged from 9-280. The average number of care professionals attending training at all branches was 60 people. Four branches stated that the cost of providing these courses was met by contract or grant provision. Three branches stated that the cost was paid by the organisations receiving the training. One branch did not specify the source of funding for this service.

## ***Befriending***

Five branches stated that they offered a befriending service for carers (Box 2.12).

### *Box 2.12: Summary of befriending activities*

- 5 out of 19 branches offered befriending services
- Most frequently provided by paid staff only (n=3)
- 3 branches provided information about the numbers of hours befriending offered to carers in October 2005
- An average of 63 hours of befriending offered to carers per branch
- All befriending services offered in people's homes
- 4 branches provided information about numbers of carers receiving befriending services in October 2005
- A total of 47 carers were provided with befriending by all branches
- 3 branches provided befriending services to people with dementia in October 2005
- Each branch provided an average of 25 hours befriending a month
- A total of 36 people with dementia were provided with befriending by the three branches in October 2005, an average of 12 people per branch

Three branches reported that their befriending services were provided entirely by paid staff (range: 1-3) while the other two relied upon a mixture of paid and volunteer staff (range in ratio of paid staff to volunteers: 2:2-1:18). Only three branches were able to provide information about the total number of hours befriending was provided to carers in October 2005. These hours ranged from 10-188 with an average of 63 hours of befriending provided to carers per branch.

All five services offered befriending in carers' homes while three of these branches also provide befriending in other locations in the community. Four branches provided information about the number of carers who had befrienders in October 2005. These ranged from 3-20 carers, with a total of 47 carers provided with befriending by all branches. Four branches identified specific grants or service level agreements as the source of funding for this service while the fifth branch

stated that befriending was provided through the family support role of the member of staff concerned.

Three branches stated that they provided befriending to people with dementia. The hours that befriending services were available in October 2005 varied from 10-44 hours, with an average of 25 hours provided by each branch. Befriending was provided at the person's home and in the community (n=2) or just in the person's home (n=1). The number of people with dementia provided with befriending in this month ranged from 5-22. A total of 36 people with dementia were provided with befriending by the three branches in October 2005, an average of 12 people per branch. Only two of the branches provided information about the source of funding for this kind of befriending (both Big Lottery grants).

### **Day Care services**

Five branches offered a Day Care service and four of these provided information about the number of Day Care places that were filled in October 2005 (see Box 2.13).

#### *Box 2.13: Summary of Day Care service activities*

- 5 out of 19 branches offered Day Care services
  - Paid staff were involved in organising all Day Care services
  - 4 branches provided information about the numbers of hours Day Care provided in October 2005
  - A total of 57 Day Care places were offered by all branches in October 2005
  - 1 branch purchased Day Care from another organisation
  - 3 branches offered Day Care services to younger people with dementia
- The number of places filled ranged from 1-30 with a total of 57 places being offered by all branches

Four branches organised their own Day Care services while one paid for Day Care from a Care Home. Of the four organising their own Day Care services, three

located it away from the branch (two had three separate locations) and one located Day Care at the branch. Three branches offered Day Care services for younger people with dementia.

All of the four branches organising their own Day Care involved paid staff (range: 3-13) while two of these involved volunteer staff (numbers not given). The other branch paid for care staff at the care home to undertake Day Care. Three branches funded their Day Care provision through contracts and/or grants. One branch paid for Day Care provision through fundraising and donations. The branch that paid a registered Care Home for Day Care had these costs met by social services.

Two branches reported that they had agreements to purchase Day Care from other providers and the numbers of places ranged from 1-2.5 per week. In these cases Day Care was purchased from Crossroads Sitting Service and a local registered Care Home. The sources of funding for purchasing Day Care in this way were fundraising and donations at one branch and funding built into support group funding at the other. One branch reported that it had an agreement to purchase Support Services from Crossroads Sitting Service but had not purchased any social support places. The funding for purchasing these places was reported to come from donations.

### ***Home Care Service***

Four branches reported offering a Home Care service (see Box 2.14).

#### *Box 2.14: Summary of Home Care activities*

- 4 out of 19 branches offered a Home Care service
- Home Care involved only paid staff
- 2 branches registered with CSCI
- A total of 126 people with dementia accessed Home Care services in October 2005

Three of these branches provided information about the staff members typically involved in the provision of Home Care. While not all information requested was forthcoming, it appears only paid staff members are involved in providing Home

Care. Two of the four Home Care services were reported to be registered with the Commission for Social Care Inspectorate.

Three branches provided information about the number of Home Care sessions provided in October 2005. Unfortunately it is not possible to define the length of a session as this information was not requested in the Audit Form. Only one branch provided information on the number of carers using the Home Care service in October 2005 (i.e. 85 carers). Three branches gave information about how many people with dementia had used Home Care in the same period. The numbers ranged from 15-85 people, with a total of 126 people with dementia using all branch Home Care services that month, an average of 41 people per service. Funding for Home Care came from contracts with the PCT, MHT or Social Services. One branch did not provide this information.

### ***General Awareness Raising, Campaigning and Publicity (GARCP)***

Fifteen branches stated that they offered GARCP (Box 2.15).

#### *Box 2.15: Summary of GARCP activities*

- 15 out of 19 branches undertook GARCP activities
- 11 branches undertook GARCP activities with paid and volunteer staff working together
- 13 branches used general branch funds/donations to pay for some or all of GARCP activities

Eleven branches said that both paid staff and volunteers were involved in service provision. Two branches relied entirely on volunteers to undertake GARCP and at one branch it was two paid staff who worked together to provide these services. One branch did not provide this information. The precise numbers of people involved (i.e. paid and volunteer workers) could not be determined from the information provided by respondents. 13 branches cited general branch funds or donations as part or wholly responsible for funding GARCP activities. Five branches used funds from contracts or grants.

### **Carer Support, Family Support and Outreach (CSFSO)**

Thirteen branches stated that they offered carer support, family support and outreach (CSFSO) (Box 2.16).

#### *Box 2.16: Summary of CSFSO activities*

- 13 of 19 branches undertook CSFSO activities
- All 13 branches used paid staff to undertake all (n=10) or part (n=3) of the activities

Of these branches all had paid staff involved in service provision, whether this was to undertake all activities (n=10) or to work alongside volunteer staff (n=3). The number of paid staff involved ranged from 1-6. At each of the three branches where volunteer staff contributed to service provision there were at least two individuals involved. More precise figures were not given by respondents.

### **Benefits and Welfare Advice**

Seven branches reported that they offered benefits and welfare advice (Box 2.17).

#### *Box 2.17: Summary of Benefits and Welfare Advice*

- 7 out of 19 branches offered Benefits and Welfare Advice
- 13 branches said they sign-posted clients to other sources of specialised advice
- These sources of advice included local benefits agencies, Age Concern, carers' resource centres and advocacy services

In total, 13 branches said that they 'sign-posted' people to other sources of specialised advice. The most frequently mentioned agencies that people were signposted to for benefits and welfare advice were local benefits agencies (n=4), Age Concern (n=4), local carers' resource centres (n=4) and advocacy services (n=3).

### **Support Groups**

#### *Carers*

17 branches reported that they offered support groups to carers (Box 2.18).

*Box 2.18: Summary of Carers' Support Group provision*

- 17 out of 19 branches offered carers' support groups
- Carers' support groups were facilitated by a mixture of paid and or volunteer staff
- Most common for branches to offer 3 carers' support groups per month
- The number of carers who attended support groups at each branch in October 2005 ranged from 4-48
- A total of 339 carers attended support groups at branches in the Yorkshire Area in October 2005
- An average of 23 carers attended carers' support groups at each branch
- Most common for carer support groups to be funded by branch general funds (n=7)

At some branches support groups were facilitated by paid staff only (n=8; range in staff numbers: 1-5) while at others they were facilitated by a combination of paid and voluntary staff (n=6; range in ratio of paid staff to volunteers: 1:1-1:8). At 3 branches only volunteers facilitated support groups.

In October 2005 the range in number of carer support groups offered each month by branches was 1-6. It was most common for branches to offer three carer support groups a month (n=6), followed by twice a month (n=5) then one group a month (n=3). Fifteen branches provided information about the number of carers who attended support groups that month. These numbers ranged from 4-48 and the total number of carers reported to have attended Yorkshire Area support groups was 339, an average of 23 carers per branch.

Among the 15 branches that provided funding information, it was most common for the provision of carer support groups to be funded by general funds/fundraising (n=7) followed by grants (n=3) or contracts (n=3). A combination of funding sources (grant, contract and/or general funds) was reported to pay for the other branches' support groups (n=2).

### *People with dementia*

Eight branches stated that they offered support groups for people with dementia (Box 2.19).

#### *Box 2.19: Summary of provision of support groups for people with dementia*

- 8 out of 19 branches offered support groups to people with dementia
- 4 branches were staffed by both paid and volunteer staff
- The numbers of support groups provided by each branch in October 2005 ranged from 1-8
- 21 support groups provided in Yorkshire Area
- A total of 138 people with dementia accessed support groups in October 2005
- An average of 6 people with dementia attended each support group held by branches in this period

One branch did not complete this section. Seven branches provided information about the staffing of support groups. Of these, four branches had both paid staff and volunteers involved in support group provision (range in ratio of paid staff to volunteers: 1:1-2:7), two branches used only paid staff (range: 2-3) and one branch used only one volunteer.

All branches offering support groups gave information about the numbers of groups held in October 2005. These ranged from 1-8 per month though it was most common for branches to offer one support group a month (n=4). In total 21 support groups were provided in the Yorkshire Area. Six branches provided figures for the number of people with dementia attending support groups during this month. The numbers of people attending groups ranged from 4-64 and in total 138 people with dementia attended support groups in the Yorkshire Area during October 2005, an average of 23 people per branch or 6 people per support group.

All branches provided information about sources of funding for support groups. These included social services (n=2), some form of Lottery Funding (n=2), general branch funds/fundraising (n=2) or a combination of sources (n=2).

### ***Outings and Day Trips***

Thirteen of the 19 branches stated that they offered outings and day trips to people with dementia and their carers and one branch did not provide this information (Box 2.20).

#### *Box 2.20: Summary of outings and day care provision*

- 13 out of 19 branches offered outings and day trips
- Staffed by both paid and volunteer staff (n=6) or paid staff alone (n=6)
- Most commonly paid for exclusively by grants (n=5)

It was most common for this service to be provided by a combination of paid and volunteer staff (n=6) or by paid staff alone (n=6). The remaining service was provided by volunteers alone. This service was most frequently paid for exclusively by grants (n=5) or exclusively by branch funds (n=4). Other branches paid for this service through a combination of grant and branch funds (n=2) or grants and self-funding (n=2).

### ***Provision of targeted support to people from BME communities***

Three branches reported that they provided targeted support to people from black and minority ethnic communities (Box 2.21).

#### *Box 2.21: Summary of targeted support to BME communities*

- 3 out of 19 branches offered targeted support
- Targeted support provided exclusively by paid staff
- Initiatives included raising awareness in communities, joint funding bids, involvement in local BME strategy group and cultural awareness training
- No specific funding sources identified

At all three branches this form of support was provided exclusively by paid staff (range: 1-5). These branches were asked to indicate the kind of initiatives that constituted this targeted support. The reported initiatives included:

- working with outreach workers in different communities to raise awareness

- giving presentations in community to different ethnic community groups
- information days or stands at community events
- joint funding bids with community groups
- involvement in local BME dementia group
- involvement in cultural awareness training

Two branches provided information about the funding used to provide this kind of support. One branch stated the funding is an element of core social services funding and the other branch stated that “most don’t cost much”.

### ***Counselling***

Two branches reported that they offered a counselling service (Box 2.22).

#### *Box 2.22: Summary of Counselling activities*

- 2 out of 19 branches offered a Counselling service
- All staff involved had a counselling related qualification but only one had a Diploma
- All staff involved at both branches received formal supervision
- Both services offered counselling to people with dementia
- In October 2005 8 carers had used one service

At one branch this service was provided by two paid staff members and a volunteer and at the other branch by one paid worker. All staff involved in counselling had counselling qualifications. One staff member had a Diploma in Counselling while all other staff had counselling skills/studies qualifications. At both branches providing a counselling service it was reported that the staff involved received formal supervision.

Only one of the two branches offering counselling provided information about the numbers of carers who had used the service in October 2005 (n=8). Both branches offered counselling to people with dementia and the numbers receiving this form of support in October 2005 ranged from 1-4. Funding for the counselling services came either from part of a social services contract or was part of the staff member’s Family Support role.

### **Grants available to people with dementia and carers**

Five branches stated that grants were available to carers and four of these branches provided information about how much was given in grants in 2005 (Box 2.23).

#### *Box 2.23: Summary of Grants available to people with dementia and carers*

- 5 out of 19 branches offered grants
- In 2005 the average amount received by each eligible carer was £102 (n=36) and the amount for people with dementia was £123 (n=3)
- Applications for grants were most commonly through use of claim form to branch (n=3)
- Funding for grants came most commonly from branch funds (n=4)

Taken together the total amount of money given in grants to carers was £3,672 and the total number of carers who received grants was 36, an average of £102.00 per carer. Three branches said that grants were available to people with dementia but only two had given grants in 2005. The total amount given in grants by the three branches to a total of three people with dementia was £368.96, an average of £123.00 per person with dementia.

Five branches described how carers and or people with dementia could apply for grants. Three branches had a claim form that could be completed and submitted to the branch while one branch required a referral, usually from a care professional. In this example it was not clear if the grants available were from branch funds or from other sources. The other branch stressed that grants to carers and people with dementia was not an advertised service and that it would be in “unusual circumstances” for this to occur. Four branches stated that funding for grants to carers and people with dementia came from branch funds (donations and or fundraising). The other branch cited a local Trust grant for holidays and access to Alzheimer’s Society national office caring funds.

### **Advocacy Service**

Three branches reported offering a specific Advocacy Service (Box 2.24).

*Box 2.24: Summary of provision of Advocacy Services*

- 3 out of 19 branches offered a specific Advocacy Service
- Advocacy Services involved only paid staff
- Main elements of services included representing carers and people with dementia at meetings, in making complaints or helping them have voices heard with other agencies
- One Advocacy Service reported providing a service to 15 people in October 2005

At two of these branches the service was provided by paid staff alone (range: 1-2) and at the other by one volunteer. Two Advocacy Services were for both people with dementia and carers and the other was for carers only. Taken together, the main elements of the Advocacy Services included:

- advice to carers support groups ('carers only' Advocacy Service)
- representation at meetings
- letters sent on behalf of clients
- supporting clients to make complaints
- help clients obtain services
- help clients have wishes taken into account
- liaising with other agencies
- attending case meetings
- attending complaint panels

Only one branch provided information about the numbers of people using their Advocacy Service in October 2005 (n=15). Two of the three services were funded by Social Services contracts while the third did not provide this information.

***Grants for Holidays***

Three branches offered carers grants for holidays (Box 2.25).

*Box 2.25: Summary of provision of Grants for Holidays*

- 3 of 19 branches offered Grants for Holidays
- 97 carers had received an average of £153.00 in 2005
- No people with dementia had received these grants

- Simple claim form obtainable from branch
- No branches purchased holidays from other organisations

Two branches reported that they had given grants for this purpose in 2005 and the total number of carers receiving grants for holidays in 2005 was 97 (range 1-96). The total amount given was £14,833, an average of £153.00 per carer. No people with dementia had received grants for holidays. All three branches had a simple claim form for carers to complete to apply for these grants. Applications were subsequently considered by the branch manager (n=1) branch committee (n=1) or by “the branch” (n=1).

Funds for this purpose of grant came from donations restricted to support carers (n=1), general funds (n=1) or a Social Services Carers’ Grant (n=1). No branches reported purchasing holidays from other organisations.

### ***Dementia Cafes***

Three branches provided Dementia Cafes and one of these was a trademarked Alzheimer Café (Box 2.25).

#### *Box 2.25: Summary of provision of Dementia Cafes*

- 3 out of 19 branches offered a Dementia Cafe service
- 1 Dementia Café was trademarked Alzheimer Cafe
- 85 people attended Dementia Cafes in October 2005
- Average of 28 people attended each service

Two branches had both paid and volunteer staff involved in providing this service (range in ratio of paid to volunteer staff: 1:6-2:5) while the other had paid staff (n=7) working on a rota with local care trust staff. The numbers of people with dementia and carers attending Dementia Cafes in October 2005 ranged from 10-50. A total of 85 people had attended Dementia Cafes at the three branches during this month, an average of 28 people per service. The Dementia Cafes were located away from branches in churches (n=1) a Friends Meeting House and Public Houses (n=1) and, non-specifically, at a Tea Dance.

## Numbers of service user contacts per branch

From all of the information that was provided by branches (Appendix 3) it is possible to make some cautious estimates of the number of service users in contact with branches. As is suggested, these estimates need to be treated with caution and should be treated as indicative rather than absolute. The reason for this 'health warning' is because the calculations are based upon extrapolation of figures for service use provided for various periods of time, including the snapshot of service use branches were asked for from October 2005 (see Table 2.1).

These figures show there is great variation between branches in terms of the numbers of people in contact during a year. This variation probably reflects a number of factors including the maturity of the branch and the geographical location. However, if nothing else the figures provide a point of discussion for branches about the extent to which they might be meeting people's needs.

*Table 2.1: Estimated numbers of service user contacts per branch per year*

<i>Branch</i>	<i>Includes website and 1x newsletter mail out</i>	<i>Excludes website but includes newsletter x1</i>	<i>Excludes day care and homecare places but includes website and 1x newsletter</i>
Barnsley	4831	4831	4831
Bradford	7017	7017	7017
Craven	7414	2950	7414
East Riding	3491	3491	3383
Hambleton	6060	6060	228
Huddersfield	5618	5618	5618
Hull and District	1252	1252	1252
Leeds	45,445*	45,445*	5869
North Kirklees	2132	2132	2132
Richmondshire	4332	4082	2316
Rotherham	1014	1014	1014
Ryedale	892	892	892
Scarborough	5206	5206	5206
Scunthorpe	420	420	408

Selby and York	3612	3612	3324
Sheffield	4202	3898	3898
Wakefield	2791	2791	751

\*Figure includes reported total annual availability of day care places

### Planned future service provision

All branches were asked to indicate whether or not they had any plans to develop new services in the near future. The reason for asking branches for this information was to provide the Yorkshire Area office with an improved understanding of branches' service development plans and the sources of funding that were being pursued. The reported plans are summarised in the table (Table 2.2) below:

Table 2.2: Planned new service provision amongst Yorkshire Area branches

Branch	Planned new service/s (start details; funding)
Barnsley	<i>Support service for people with dementia</i> (Mid 2006; donations and fund-raising; 2 additional part-time staff) <i>Holiday for carers and people with dementia</i> (2006; subsidised by donations and fund-raising)
Bradford	<i>Kaleidoscope Café</i> (March-September 2006-; 'left over' HCFT funding) <i>Carer respite service</i> (April 2006-; in partnership with Crossroads funded by the Big Lottery)
Calderdale	-
Craven	-
Doncaster	<i>Tandem Befriending Scheme</i> : 2 or more paid befrienders (June 2006; writing grant application) <i>Tandem Dementia Café</i> (June 2006; actively planning and funding sources being explored)
Hambleton	-
Harrogate	-
Huddersfield	-
Hull and East Riding	<i>'Making it Happen' person-centred care conference</i> (June 2006; funded jointly with health and social services)
Kirklees	-
Leeds	-

Rotherham	<i>Advocacy</i> <i>Dementia Care Worker</i> <i>Befriending</i> (2006; exploring funding sources for each potential service)
Richmondshire	<i>Break-Free Centre</i> (April 2006-; branch funds)
Ryedale and Whitby	<i>Development Officer post</i> (2006; exploring Lottery as funding source) <i>Monthly Drop-in</i> for people with dementia and carers (2006; in planning)
Scarborough	<i>'Forget me not'</i> service for recently bereaved carers and people with relatives in long-term care (2006; planning)
Scunthorpe	<i>Paid trained workers</i> to raise awareness and information provision (2006; writing funding bid)
Selby and York	-
Sheffield	<i>Home Care support service</i> (Feb 2006; outline application for 3 years funding submitted with aim to begin 2007/8) <i>Advocacy Service</i> (2006; seeking statutory funding to begin 2007/8)
Wakefield	<i>Carers' support group</i> (2006; operational, funding unknown)

### **Dementia care services or dementia forums in branch areas**

Branches were also asked to provide information about other dementia care services or dementia forums that exist in their areas. The purpose of asking a branch for this information was to discover what other services each branch was aware of and to provide the Yorkshire Area Office with an overview of the other agencies that branches might be working in partnership with or could work in partnership with in the future. Information was not required about local residential or nursing homes providing services for people with dementia. Table 2.3 summarises the dementia care agencies identified by each branch.

Table 2.3: Dementia care agencies and dementia forums in each branch area

<i>Branch</i>	<i>Dementia care agency or dementia forum</i>
Barnsley	-
Bradford	<ul style="list-style-type: none"> <li>▪ Social Services Specialist Resource Centres (4; day and respite care)</li> <li>▪ Memory Assessment and Treatment Service (Care Trust in 2 PCTs)</li> <li>▪ Memory Clinic</li> <li>▪ Social Services 'Day Club' for YPWD</li> <li>▪ Dementia Outreach Service (Holmewood Resource Centre in Airedale PCT area)</li> <li>▪ Advocacy (Older people's mental health advocate at</li> <li>▪ Bradford &amp; Airedale MH Advocacy group)</li> <li>▪ Day Care (Several voluntary centres)</li> <li>▪ Live at home schemes (not specifically for PWD but will befriend)</li> <li>▪ 'Sitting' service (not specifically for PWD but nearly all sitters have PWD and do some training for this)</li> <li>▪ Health Service Care Trust (assessment ward at Cheelow Lodge, Daisy Hill House, Bradford, and Ward 24, Airedale)</li> <li>▪ Ward 24 ('action group' of carers and friends)</li> <li>▪ Chellow Lodge (carers' group)</li> <li>▪ 3 of the 4 resource centres (carers groups either affiliated to or attended by Alzheimer's Society staff)</li> <li>▪ Carers' Resource and Carers Connection (some carers of PWD use their services)</li> <li>▪ BME Outreach Project 'Meri Yaadain'</li> </ul>
Calderdale	-
Craven	-
Doncaster	<ul style="list-style-type: none"> <li>▪ Assessment Unit</li> <li>▪ Memory Clinic</li> <li>▪ Day Respite Services</li> <li>▪ Older People Social Services</li> <li>▪ Community Mental Health Team</li> <li>▪ Younger Onset Dementia Service</li> <li>▪ Forest Gate Day Hospital</li> <li>▪ Age Concern</li> <li>▪ User and Carer Forum</li> </ul>

	<ul style="list-style-type: none"> <li>▪ Carers' Forum</li> <li>▪ Mental Health Awareness Group</li> <li>▪ Older Persons Partnership Board</li> <li>▪ Older Peoples Mental Health Services Governance Group</li> <li>▪ Older Peoples Dementia Services Collaborative</li> </ul>
Hambleton	<ul style="list-style-type: none"> <li>▪ Initial Assessment Provision (Community Mental Health Team)</li> <li>▪ Memory Management group (Community Mental Health Team)</li> </ul>
Harrogate	-
Huddersfield	-
Hull and East Riding	<ul style="list-style-type: none"> <li>▪ Dementia Collaborative Service (Bridlington)</li> <li>▪ Rethink</li> <li>▪ MIND</li> <li>▪ VERNA (care provider)</li> <li>▪ New Concept Care (day care providers)</li> <li>▪ Occupational Health</li> <li>▪ Social Services</li> <li>▪ Community Mental Health Teams (Humber Mental Health Teaching NHS Trust)</li> <li>▪ In-patient provision (Humber Mental Health Teaching NHS Trust)</li> <li>▪ Intensive Home Care Team (Hull, Humber Mental Health Teaching NHS Trust)</li> <li>▪ Day Services provision (Hull Humber Mental Health Teaching NHS Trust)</li> <li>▪ Younger Peoples' Memory Team (Humber Mental Health Teaching NHS Trust)</li> <li>▪ Memory Clinic (over 65s) (Hull; Humber Mental Health Teaching NHS Trust)</li> <li>▪ Carer Support Services (Hull and the East Riding)</li> <li>▪ A wide range of voluntary and private providers (not specified)</li> </ul>
N. Kirklees	-
Leeds	-
Rotherham	<ul style="list-style-type: none"> <li>▪ Younger people with dementia day care (Richmond Fellowship)</li> <li>▪ Day Hospital</li> </ul>
Richmondshire	-
Ryedale and	<ul style="list-style-type: none"> <li>▪ The Carers Resource (Pickering)</li> </ul>

Whitby	<ul style="list-style-type: none"> <li>▪ Alzheimer’s Society branch (Scarborough)</li> </ul>
Scarborough	<ul style="list-style-type: none"> <li>▪ Cedar Wood (Day Hospital)</li> <li>▪ Rowan Lea (Assessment Unit)</li> </ul>
Scunthorpe	<ul style="list-style-type: none"> <li>▪ Scunthorpe Hospital Carer Unit</li> </ul>
Selby and York	-
Sheffield	<ul style="list-style-type: none"> <li>▪ Extensive list provided but not included here for economy of space</li> </ul>
Wakefield & 5 Towns	<ul style="list-style-type: none"> <li>▪ Memory services (Fieldhead Hospital)</li> <li>▪ Community Units for the elderly (Day care/respice care for people in the later stages)</li> <li>▪ Resource Centres (Day care/respice care)</li> </ul>

### **Collaborative work in progress**

Branches were asked to report any collaborative activities that they were engaged in with other organisations. The idea here was to identify existing ‘partnership working’ and provide examples to other branches in the Yorkshire Area of where they might seek to establish partnerships with other agencies in their areas. At the time when branches completed the Audit Form only Bradford and Sheffield branches reported examples of collaborative working and these are summarised below (Table 2.4).

*Table 2.4: Examples of existing collaborative work between branches and partner agencies*

<i>Branch</i>	<i>Current collaborative work</i>
Bradford	<ul style="list-style-type: none"> <li>▪ ‘Taking Time’: (a group which includes some branch workers plus volunteers. It undertakes training in reminiscence and sessions in care homes)</li> <li>▪ Bradford Dementia Group (reminiscence project for carers and people with dementia)</li> <li>▪ Bradford Dementia Group and York University (‘Partnering your Doctor’ project involved 16 carers and PWD in two workshops)</li> </ul>
Sheffield	<ul style="list-style-type: none"> <li>▪ Sheffield Care Trust ‘caring and coping’ and ‘coping with forgetting’ initiatives: (involvement varies from allowing activities to run on branch premises, through to staff providing some input to facilitation. Branch also on steering group for each of these activities).</li> <li>▪ Commenting on research proposals</li> </ul>

	<ul style="list-style-type: none"><li>▪ Chairing citywide groups/activities</li><li>▪ Participating in reviews of services</li><li>▪ Personal Assistance Days (National AS)</li><li>▪ Computer Clubs (National AS)</li><li>▪ Early Awareness Campaign (National AS)</li></ul>
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### *Summary*

This section has included a detailed description of branch service activities, planned service development, examples of the knowledge each branch has of other dementia-related organisations in 'their' areas and existing collaborations with other agencies. The main observation is that there is huge variation between branches in the provision of services to carers and people with dementia. Within this there are clearly some difficulties experienced by branches in the collection of information about what they do provide and to whom. What is notable is that few services are offered by branches to people with dementia. Also, few branches are currently collaborating with other dementia agencies. These observations are taken up in the discussion (Section 6) and suggestions are made for ways to address areas of concern (Section 8).

### **Section 3: Pilot Branch Initiatives**

A total of six branches were chosen to be pilot branches for the PIP project. The rationale behind the idea of the project of having pilot branches was to seek to use PIP funds and the impetus of the project to organise modest initiatives at each of the branches focused around the PIP project key themes of partnership and/or inclusion. To this end the Yorkshire Area Office chose three focal themes: urban inclusion, rural inclusion and black and minority ethnic communities. The six branches that were chosen were selected on the basis that each was dealing with practical issues relating to one of the focal themes. The six branches are listed below under the three focal themes:

#### Black and Minority Ethnic Communities

Bradford; Huddersfield.

#### Urban Inclusion and Partnership.

Sheffield; Hull and East Riding\*(\*Hull and East Riding branches formally merged in April 2006)

#### Rural Inclusion and Partnership

Richmondshire; Barnsley.

What follows is a description of the initiatives undertaken at each of the branches and includes a brief explanation of why the initiative was chosen.

#### **Black and Minority Ethnic Communities**

##### ***Huddersfield***

Huddersfield branch is located in the centre of the town. The town itself has a number of distinctive ethnic minority communities. In discussion with the branch it was acknowledged that few people from these communities current use branch services and, further, that the PIP project offered an opportunity to explore why this was and how any identifiable 'barriers' to service use might be overcome. It was decided that a half day conference would be arranged to bring together people from Black and Minority Ethnic Communities to talk about the actual and perceived role of the Alzheimer's Society in the town and to identify possible barriers to increased service use.

### *Invitations*

Letters of invitation were sent to all known community organisations and relevant health and social care professionals in the town. These included all GPs listed as currently working in the south Kirklees area. In addition, an advert was purchased in the Huddersfield local paper to invite interested members of the public to the event.

### **Overview of the conference**

Janet Dudley (Huddersfield branch manager) read a letter written by Thelma, a local woman of African-Caribbean heritage. In this letter Thelma described her own experience of caring for her father and said that she had been well supported by the Alzheimer's Society. However, she felt that many people with a similar heritage to her own did not realise that the Alzheimer's Society's help was completely confidential and so did not make contact with the Huddersfield branch.

A local man, Mr Mick Guha, eloquently recounted to delegates what it was like to care for his wife. Mr Guha described dementia as 'the silent killer' and said he had faced certain problems that he was sure other people from Black and Minority Ethnic communities also face. These included the different expectations amongst staff in care homes about the kind of food wanted by people originally from the Indian subcontinent and the time of day when people wanted to eat. He also described the effects that dementia can have on people of his wife's generation, such as reverting to their first language, be it Hindi, Urdu or Gujarati. Care staff had thought his wife was talking 'nonsense' but this was because they simply did not understand these languages.

Also speaking at the conference was Komel Evans, a Community Psychiatric Nurse (CPN) for Older People, with particular responsibility for people with South Asian heritage. Komel explained that her role was to give support to people experiencing memory problems and confusion, two of the main symptoms of dementia, and also help with the process of seeking a diagnosis of dementia.

### *Discussion Groups*

Delegates broke into groups and were asked to think about two questions: reasons why the Alzheimer's Society was not attracting many people from Black and Minority Ethnic communities and also possible barriers within Black and Minority Ethnic Communities which prevent people in those communities being more aware of the Alzheimer's Society.

*Possible reasons the Alzheimer's Society is not providing more support*

A number of reasons were put forward by delegates as to why the Alzheimer's Society was not providing more support to people from Black and Minority Ethnic Communities. These are summarised below (Box 3.1).

*Box 3.1: Possible reasons the Alzheimer's Society is not providing more support*

- Perceived as a 'white organisation'
- The name 'Alzheimer's' is vicious, serious and scary as opposed to say 'memory loss'
- Dementia implies there is 'no chance'
- People don't want their privacy invaded
- Heritage of A.S: need to get better at asking what people want, approaching people from Black and Minority Ethnic communities with an open mind
- Lack of awareness about the work of the Alzheimer's Society
- Lack of clarity about what 'Alzheimer's' means? This is a problem with the perception of 'dementia'
- Lack of outreach service
- Wider issue of people from these communities identifying themselves as 'carers'
- The Alzheimer's Society has not adequately taken services into communities and this is vital
- People from Black and Minority Ethnic Communities are afraid to talk with others
- It was noted that it is easier to talk with others at, e.g. coffee mornings; and the Alzheimer's Society could target mosques
- Funding limitations experienced by the Alzheimer's Society
- Access: for some it might be hard to travel to reach existing services provided by the Alzheimer's Society
- A combination of issues around communication, language, mindset and social class. In addition, differences between the Alzheimer's Society and the people it seeks to reach in terms of the dominant culture, faith and associated beliefs
- Lack of trust between the Alzheimer's Society and the people it seeks to reach
- Infrequency of contact between Alzheimer's Society and people from Black and Minority Ethnic communities.

### **New approaches or strategies that the Alzheimer's Society could adopt**

Following on from discussion of the possible reasons why the Huddersfield branch was failing to provide more support to people from Black and Minority Ethnic communities, delegates made a number of suggestions for new approaches or strategies that might be adopted to improve the situation (see Box 3.2).

#### *Box 3.2: Approaches or strategies the Alzheimer's Society could adopt*

- Aim to support people with 'memory loss' not dementia or Alzheimer's disease. Memory loss provides another 'common cause'
- Avoid stigma by emphasising the physical problems (not the mental problems) associated with dementia and how the Alzheimer's Society can help
- Go to BME community groups and talk. Ask the person – what do they want from the AS?
- Give forms of support a discreet or different name, e.g. the Friday Club
- Existing voluntary and statutory organisations could work together and or seek funding together
- People from the target communities may want a different resource to that currently offered by the Huddersfield branch
- Alzheimer's Society to appreciate that people in Black and Minority Ethnic communities don't necessarily want to relive or talk through problems – they may want relief and practical help
- Identify weaknesses in system
- The Alzheimer's Society need to engage earlier with people as if too late people's behaviour makes them difficult to place
- People from the target communities may not read existing Alzheimer's Society leaflets. Perhaps the branch should seek to communicate its services through e.g. talks, a play or even a puppet show

### **Barriers within BME communities that may prevent people from these communities being more aware of the Alzheimer's Society's work**

Delegates were also asked to think about the barriers that may exist within Black and Minority Ethnic communities which could impede people with dementia and their carers finding out more about the support and services offered by the Alzheimer's Society. Where possible, delegates were also asked to suggest ways to overcome these barriers (see Box 3.3).

### *Box 3.3: Barriers within BME communities to awareness of Alzheimer's Society*

- A lack of knowledge about the organisation and dementia more generally was suggested. A way to overcome this barrier would be to improve training and, in so doing, skills and knowledge in these communities
- Infrastructure: a lack of ways in which to signpost people with dementia and their carers to the Alzheimer's Society
- Overall, it was suggested that the vision of being more inclusive needed to be backed by commitment. One suggestion was for a BME Worker to be appointed at the Huddersfield branch
- Refugees: new immigrants to the town may not have developed sufficient networks to come into contact with the Alzheimer's Society
- Faith: people from Black and Minority Ethnic groups may not approach the Alzheimer's Society because of reasons associated with their faith or beliefs
- A further suggestion to tackle barriers in the target communities was to ensure the distribution of culturally appropriate leaflets and, perhaps, audio cassettes

### **How can the Alzheimer's Society and people in the communities and their representatives improve the ways they work together?**

In an attempt to bring together the ideas from the earlier discussions delegates were asked to suggest ways in which the Alzheimer's Society and community representatives could improve the ways they work together. The suggestions are summarised in Box 3.4 below.

### *Box 3.4: Improving ways of working together*

- The Alzheimer's Society could target work with younger people from Black and Minority Ethnic communities as they may need to know in the future
- Look at use of available resources: Carers' Gateway issue a newsletter and have a database and so does the Huddersfield branch. Could these resources be pooled?
- Start a Kirklees Partnership Group that seeks to bring together people from all communities to talk about support for people with dementia and their carers
- The Alzheimer's Society needs to consider how it currently promotes itself to people with dementia and their carers in all communities and seek to review this in light of today's discussions. That is, a review of its marketing, contact with GPs, profile in Memory Clinics and libraries. This would help to improve sign-posting

- The Huddersfield branch could arrange to give further talks to community outreach groups
- The Alzheimer Society could draw upon its experiences in other areas with diverse ethnic communities and in adopt best practice in Huddersfield

### **Action Plan**

A tentative Action Plan was drawn up by delegates to build upon the momentum created by today's conference. The Action Plan was intended to state firm commitments by delegates (see below) but instead resembled a statement of principles:

- Form a partnership group with common aim of 'Fighting memory loss'
- Work together in community events
- Work together better
- Initiate an advertising campaign (radio/TV/newspaper)
- Seek funding for a specific worker (appropriate language; remit to work one to one)
- Alzheimer's Society and community groups to put in a joint funding bid
- Go that step further

### *Reflections*

The main message of the day was that the Alzheimer's Society needs to continue to find new ways to engage with Black and Minority Ethnic Communities in Huddersfield. This will be the way for these communities to begin to develop trust in the organisation and increasingly access and shape the support that is offered. The commitment and enthusiasm of those present today suggested there was the appetite to move this process forwards.

Since the half-day conference was held a report on the day has been sent to all participants by the Alzheimer's Society Huddersfield branch. Janet Dudley, branch manager, has invited all participants to an event the branch is organising in July and has suggested a date for a follow-up meeting on the issue of inclusion. In June, the Huddersfield branch manager Janet Dudley was asked to reflect on the half-day conference and whether or not it had been a success. Her thoughts appear below:

*"Meeting the challenges..' is definitely an appropriate title...Whilst it was relatively easy to identify appropriate people and organisations to invite to*

*the half-day conference it was difficult to ensure they engaged in the event.*

*Although the attendance was low ( from over 100 invitations there were 16 replies, this included 4 apologies from GP's, 4 people unable to attend but wanting to be kept informed and 13 attendees), the small group that did attend were keen to ensure the issues of black and ethnic minority groups are addressed.*

*As a result of the event we have now identified a small group of people who wish to be involved in taking this work further. It was noted that pressure on time for Alzheimer's workers made it difficult to progress this work however further funding has been located to enable a series of meetings with the hope that we will be able to discuss how best to work within the local community. This ultimately may be achieved by applying for funding to recruit a dedicated worker.*

*Good links have been made with workers within the community and as the saying goes - 'from little acorns do big oak trees grow'."*

### **Bradford**

A number of different ideas for an initiative at Bradford branch, supported by the PIP project, were discussed in the early months of 2006. The branch manager, Ruth Gallagher, was particularly keen to ensure that any initiative that was undertaken should be useful to the branch and local communities in the long term. Unlike the other PIP initiatives, Bradford branch took full responsibility for planning and undertaking the work it chose to undertake. As a result of this the rationale and outcomes of the initiative are described below by Ruth Gallagher.

*"Bradford is a diversely populated city. Although its largest minority originates from Pakistan, there are many from India, Kashmir, Eastern and Middle Europe, African-Caribbean and many African countries, people from Ireland and then some others! So it was reasonable for our branch to look at inclusion from this perspective.*

*Bradford itself received government money last year from an application made by health and social services and the branch for raising awareness of dementia within the South Asian communities. The project, Meri Yaadain began around the same time as the PIP project, so it was sensible for us to use the time and funding to participate thoroughly in that outreach programme – especially as we were already involved. To do otherwise would have given out entirely wrong messages about inclusion.*

*The branch manager and support workers have worked with Meri Yaadain's two workers to plan a conference and a number of roadshows. There have been 4 'ideas and planning' meetings plus an educational day with the branch as part of their induction. We have attended and spoken at 5 roadshows with Urdu, Punjabi, Pushtu and Bangladeshi speaking women of all age ranges. The Meri Yaadain Conference drew men and women from many South Asian communities. Further roadshows and another conference are coming up this year.*

*Problems encountered have been the lack of learning and educational materials in other languages, fitting things into our tight schedules, the reluctance of some of the community centre managers to let the workers go there or to encourage their members to attend the conference. There has, surprisingly, also been some indifference to the workers by BME staff in other sections of statutory services – we have tried to explore this and improve things. There is sometimes some lack of understanding from non-BME community groups about the need for and benefits of such a project.*

*The plus points are many. The roadshows are informal, including refreshments, which gives an easy atmosphere to chat. The branch has been able to meet groups it has not reached before and probably would struggle to do so unaided. People are interested because they recognise dementia in their communities although there is no word for it. Our Family Support Worker (a Punjabi and Urdu speaker) who works within the Memory Assessment Service has made links with communities who may attend the clinic. The relationship between the project workers and the branch is excellent making referrals and joint working possible. We have worked on challenges together.*

*And the learning? It has been made very clear at all events that South Asian communities do not want written materials, even in their own languages. 'No more leaflets, please' was very clear. In the older generation, not everyone reads. The younger generation may speak a language but seldom reads it. We have been asked very clearly for audio and visual materials. For presenters, there is the challenge of making an understandable presentation with as little verbiage as possible. For example, brain scan pictures created interested and animated discussion and the kind of understanding which we strove for – much more than pictures of an Asian carer helping an Asian person with dementia, which explained nothing!*

*We are also beginning to explore what communities consider appropriate care - rather different from the ways it is usually delivered. There are issues of distrust of doctors, the way families should behave and the ever-increasing pull between cultures which many people, especially women, find themselves experiencing.*

*The urgent need is to create spoken and visual materials to educate about dementia, so this is what we will be doing in the next few months. The long-term needs bring issues which must be tackled by statutory services and the community together if person-centred care is to be a reality.”*

## **Urban Inclusion and Partnership**

### ***Sheffield***

In discussions with Sheffield branch manager, Judith Gregory, it was evident that the Sheffield branch currently participates in a city-wide older people's mental health forum. However, there have been some difficulties engaging with smaller, area-specific community and faith based organisations. Judith said that she was concerned about this lack of engagement as it might result in people with dementia, their carers and families from certain sections of the Sheffield community or geographical areas of Sheffield, missing out on support offered by the branch. In addition, the lack of information about these communities and their needs that follows from current poor lines of communication might also mean that branch services are not delivered in ways judged to appropriate by people from certain sections of the local population or areas of Sheffield.

### *Questionnaire*

Judith Gregory was asked to identify a short list of questions to ask representatives from the community and faith-based organisations previously identified by the branch. These were focused around seeking to discover the representatives' perceptions and knowledge about the Alzheimer's Society Sheffield branch, whether they had previously referred people to the branch from their organisation and whether or not there might be opportunities to discuss and ideas for future partnership working with the branch.

As of June 2006 the questionnaire has been sent to faith groups and small community organisations in Sheffield. The responses are expected in mid-July at which point they will be analysed and a report will be sent to Sheffield branch for distribution to the contributing organisations.

### ***Hull and East Riding branch***

During the early months of 2006 the hitherto separate branches of Hull and East Riding were in the process of merging. This caused some disruption to the branch's participation in the PIP project. However, in March the then manager of Hull and District branch, Julie Hastings, suggested that an opportunity existed for the priorities of the PIP project to be taken forward as part of an existing plan for a city-wide conference on person-centred care for people with dementia. This conference, held on June 27<sup>th</sup>, was organised by the Hull and East Riding branch in conjunction with key statutory and voluntary sector health and social care professionals.

Through contact and discussion with Janet Woodhouse, nurse at the Hull Royal Infirmary Memory Clinic, it was agreed that formal letters of invitation and booking forms were sent out. The questionnaire was devised by DR and, following discussion with Janet, it was agreed that the document would be focused on asking prospective delegates whether they felt there were any geographical areas of Hull and East Riding that currently lacked services, whether delegates could identify any sections of the new branch area community experiencing unmet need and whether delegates could suggest any future partnerships between the Alzheimer's Society and other voluntary and or statutory organisations.

On the 27<sup>th</sup> of June 2006 the recently merged Alzheimer’s Society Hull and East Riding branch took part in ‘*Making it Happen*’, a conference in Hull aimed at promoting person-centred dementia care. A few weeks prior to this conference David Reid designed and distributed a brief questionnaire to prospective delegates. The purpose of the questionnaire was to ask delegates for their opinions about the branch’s services – in particular, about issues of rural and urban inclusion and potential partnership working.

*Who completed the questionnaires?*

The ‘type’ of respondents to the questionnaire is shown in Table 3.1:

*Table 3.1: Respondents*

<i>Type of respondent</i>	<i>Number</i>
People with dementia	2
Carers	2
Mental Health care professionals	4
Social Services care professionals	4
Voluntary sector care professionals	1
Other care professionals or paid workers	5
<i>Total respondents</i>	18

None of the people who completed questionnaires were registered disabled. Of the 18 people who completed questionnaires, 6 lived in rural areas of Hull and East Riding, 10 lived in urban areas and 2 people lived outside the Hull and East Riding area.

## **RESPONSES FROM QUESTIONNAIRES**

### **Equal access to services**

#### *Rural*

Table 3.2: Does the branch offer people in rural areas equal access?

<i>Response</i>	<i>Number</i>
Yes	1
No	4
Don’t know	13
<i>Total</i>	18

People were asked whether or not they thought the Hull and East Riding branch offered people in rural areas equal access to its services (Table 3.2). A total of 13 people stated that they did not know. One respondent felt it did while a further four felt it did not

### *Urban*

Table 3.3 Does the branch offer people in urban areas equal access?

<i>Response</i>	<i>Number</i>
Yes	5
No	2
Don't know	11
<i>Total</i>	<i>18</i>

People were asked whether or not they thought the Hull and East Riding branch offered people in urban areas equal access to its services (Table 3.3). Eleven people stated that they did not know. A total of 5 people felt it did while a further two felt it did not.

### Comment

The main issue that appears to arise from these responses is with regards to knowledge about branch services amongst the respondents. The majority did not feel sufficiently well-informed to comment. This is a theme that recurs later in this report.

### **Improvements in services to rural areas**

People were asked to describe any specific improvements they would like to see in the Hull and East Riding branch's provision of services to people living in rural areas of Hull and East Riding. Amongst the respondents there were seven specific suggestions made. Given that 13 respondents felt they did not know whether the branch offered equality of service to people in rural areas this level of response suggests two people may have been commenting with limited knowledge of service provision. The suggestions appear below:

*"I work a lot in the rural areas in the Hull and East Riding area and I have found it difficult to access Alzheimer's Society within these area [sic] (due to the limited resource available to them. It would be useful to have some permanent access for clients within these areas (although I understand how difficult this is in terms of funding)" (care professional, mental health).*

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*“Difficult for people living in rural areas to access support groups; transport or outreach service”* (care professional, social services).

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*“More publicity, awareness of branch, it’s services and activities”* (care professional, voluntary sector).

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*“Need to clarify existing provision however 1:1 home support; financial advice; legal advice; information on services; information on carers’ support and ongoing support (not just carer focused)”* (care professional, mental health).

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*“A larger base to work from and a higher amount of capital, per head of population, in Hull and East Riding as the current base does appear very limited compared to other areas of the country”* (day centre manager, social services).

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*“More men to provide respite care of a few hours to allow carer’s “respite”. Perhaps members of other groups e.g. pager [?] could volunteer for this duty”* (carer).

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*“More publicity as to where you are and what help is available from the organisation”* (care professional).

### Comment

Three people commented on specific improvements to information provision or publicity about branch services. These comments chime with earlier comments about not knowing what the branch offers. One person highlighted experience of difficulties accessing the branch and another suggested the branch base could be bigger. With the merger of the two branches this raises a question for the new branch about where its services are provided in the region. One person said it was currently difficult for people to access support groups. Finally, one person felt that it would be useful if more men were available to offer respite, a suggestion that did not seem to be aimed specifically at the branch

### **Improvements in services to urban areas**

People were asked to describe any specific improvements they would like to see in the Hull and East Riding branch’s provision of services to people living in urban areas of Hull and East Riding. These suggestions and comments are presented below:

*“From a ‘professional’ view more visiting teams with information. Ongoing to enable workers to provide information”* (care professional, social services).

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*“More publicity, awareness of branch, it’s services and activities”* (care professional, voluntary sector).

---

*“More publicity as to where you are and what help is available from the organisation”* (care professional).

---

*“Better links with social services; better links with Age Concern; Better developed advocacy for people with dementia in Hull and East Riding; Develop training to be made available to private and independent organisations in Hull and East Riding”* (care professional).

### Comment

Three of the comments focus on improvements that respondents would like to see in information provision and publicity of the services on offer. Again, as with the suggestions made for improvements to rural areas, the branch may need to consider how to increase its profile with relevant organisations in urban areas. A further comment challenges the branch to foster better links with other agencies, to improve the provision of advocacy services and to offer dementia-related training to other organisations.

### **Geographical focus**

In the questionnaire people were asked to identify any geographical areas of the Hull and East Riding region where they thought the Alzheimer’s Society could do more to support people with dementia and their carers. Where areas were identified, respondents were asked to suggest how the branch might achieve these improvements. However, of the five suggestions that were made about areas where services might be improved, only two suggested how this might occur:

*“Pocklington, Goole, Beverley”* (care professional, mental health)

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*“All areas – as above...More publicity, awareness of branch, it’s services and activities”* (care professional, voluntary sector)

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*“Day Care in ER...”* (care professional, mental health).

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*“Anlaby; Swanland; Cottingham; Hessle”* (care professional, day care services).

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*“Wolds villages, Driffield and Bridlington Districts and surrounding villages. Again publicity is needed – leaflets etc not just a website – not everyone has a computer”* (care professional).

### Comment

These suggestions highlight specific geographical areas of the Hull and East Riding branch area where people feel services could be improved. Some are areas on the outskirts of Hull and others are in rural East Yorkshire. Whether these comments reflect a lack of information about the support available in these areas or a simple absence of services needs to be made clear. The question of the availability of day care in East Riding may also be worth consideration by the branch.

### **Anything else and ideas for future partnership working**

In the final section of the questionnaire respondents were asked to highlight any other issues they wanted to raise and suggest any possible future partnership working. Some of the suggestions were personal:

*‘And a lot of help from [named] Clinic. Hoping to Help my self and others. I have Mrs [name] gives me a run out into the countryside which I look forward to. And home help to keep things tidy and clean, shower and shop. Helping to live again’* (person with dementia).

Other comments were pitched at a more strategic level for the branch to consider and these included suggestions for improved collaboration and, particularly, information-sharing and partnerships:

*“Strengthening partnerships within the acute trust, by information sharing about what the society can provide in communities could enable us to pass this on to carers such as contact numbers etc”* (care professional, NHS hospital).

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*“Rural areas: - access and support improved for people with dementia and their families; development of partnerships with NHS services for smoother access to different*

*supportive agencies (moving support into the community and away from NHS mental health service and the stigma round this)” (care professional, mental health).*

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*“Information packs available at local hospitals for patients attending clinics associated with memory loss/dementia so that they and their carers are aware of the Society and the help and advice available from an early stage in their illness” (carer).*

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*“Working more closely with other voluntary organisations to develop links and work in partnership better” (care professional, voluntary sector).*

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*“I manage learning disability services in the Bridlington area. It presently includes an ageing population of individuals with “Downs Syndrome”. The impact on the lives of families and individuals who are affected is rapid, and devastating. Any information to help identify, prevent and work with will be most useful” (care professional).*

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Other suggestions appeared to be led by specific concerns felt by respondents and were not necessarily to do with Alzheimer’s Society branch activities:

*“Essential to consider mood disorders in presence of dementia and sign-post to appropriate services; greater emphasis in dementia literature; awareness of carers, volunteers and paid staff ; Preventative strategies; prevention of mental health problems for carers and psycho-social interventions awareness/research c.f. drug therapy...” (care professional, mental health).*

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*“It would be helpful if bus services are not taken off rural areas or a private company could run between areas so the elderly don’t feel isolated. Also a voluntary service for people to do some cleaning and the windows for them as this is important to a lot of elderly who don’t have any family and cannot do this themselves” (care professional, day services)*

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However, a number of respondents returned to the recurring theme of general levels of awareness about branch service activities:

*“The local branch does very little to promote itself and its services that are offered. There appears to be no medium to long term strategy developed to promote and educate people in Hull and East Riding about dementia. There appears to be very limited support*

*for families and informal carers by Alzheimer’s Society in Hull compared to other areas” (care professional, day services).*

*“We have people who use our service who have dementia and have not really had much contact with the Society. We really need to get to know more about how we can help each other” (care professional, day services).*

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*“Would be useful to know what sort of services you provide. Maybe useful to spend time with each other – develop networks” (care professional, social services).*

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*“I have a limited knowledge about the full workings of the Alzheimer’s Society currently – therefore, it is difficult to comment upon what improvements could be made” (care professional, mental health).*

## **Summary**

This review of the results of the PIP questionnaire summarises a small and non-representative survey of opinion about rural and urban inclusion and partnership amongst those connected with the Alzheimer’s Society Hull and East Riding branch. Though there was satisfaction expressed by respondents about the services currently provided the main aim of the survey was to ask stake-holders about where they could identify areas for improvement. To that end it is clear from these small number of respondents that the new branch could consider the following recommendations:

### *Recommendations*

- Rethink the branch’s publicity strategy in order to raise general awareness about what services the branch is providing.
- Consider seeking to improve its service provision in rural areas of East Riding and towns on the edge of Kingston-upon-Hull so that service provision is more equally distributed around the branch area.
- Take the lead in building upon the firm interest shown by statutory and other voluntary organisations in partnership working.
- Consider developing dementia training services for relevant organisations in the Hull and East Riding branch area.
- Consider developing a dementia education strategy for people with dementia and their carers in the branch area.

- Consider forming a more coordinated outreach-orientated dementia information service to ensure health and social care professionals are well-equipped to pass on Alzheimer's Society information and advice to people with dementia and their carers.

## **Rural Inclusion and Partnership**

### *Richmondshire*

In discussions with Richmondshire branch it became clear that it was a priority to develop their existing volunteer led information centre, based in Leyburn, as it was not being well used. The vision emerged of *“a centre where carers could come with the person they care for to enjoy a chat with refreshments, and have the opportunity to leave the person with dementia for a while in safety and go shopping”* (Pam Crawford, branch manager).

A small Lottery 'Awards4All' Grant was obtained by the branch but additional funding from the PIP project led the branch to consider more carefully how to include other local organisations. To promote the new *Break Free Centre* and seek potential partnerships with other agencies it was decided that the PIP project would support Richmondshire branch to host an introductory meeting for associated health and social care professionals and potential volunteers. In practical terms this meant that DR assisted sending invitations to all the GPs in Leyburn and surrounding areas, to known individuals at appropriate voluntary and statutory agencies and representatives of organisations that might have an interest in supporting the Break Free Centre.

On March 24<sup>th</sup> a meeting was held at what would be the location of the weekly Break Free Centre, The Friends Meeting House in Leyburn. Of the GPs who were contacted only one sent his apologies and asked for a summary of the day's proceedings. However, the promotional meeting was attended by representatives of the local carers' organisation, the local advocacy service, a local residential/nursing home and the local council. In addition, the local branch of Age Concern had responded by phoning Richmondshire branch (and later attending a meeting) to state that they would like to provide an exercise class at the Break Free Centre on a regular basis.

After the promotional meeting, commitments to 'guest-spot' at the Centre were also forthcoming from the Carers' organisation, the local benefits agency and the local advocacy group. The Break Free Centre began on Friday 28<sup>th</sup> of April. The opening ceremony was attended by a Director of the PCT and by volunteers, carers and two people with dementia. Following this, the Centre has been open each Friday morning. Commitments made by the agencies noted above have been formalised in a 3 month 'timetable' of events that has been distributed by the branch and these other organisations. Sessions were booked by 4 local organisations, between 1 and 4 sessions on several Fridays during first 3 months. Advice offered would include Benefits Rights, Advocacy issues, making difficult decisions, long term residential and nursing care, transport difficulties and an Age Concern exercise class.

In June 2006, Pam Crawford was asked to reflect on what worked well, what could be improved and ways forward for the Break Free Service. Her views appear below:

*What has worked well?*

- A rota of 18 volunteers has been recruited – most are carers or ex carers, some are ex committee members. 3 volunteers are willing to attend the centre each Friday
- A total of 10 people with dementia have attended the Centre since opening.
- A total of 8 carers have attended
- The Quaker Meeting House is an excellent venue with plenty of space, kitchen facilities and gardens
- Other local organisations have attended the centre to provide advice sessions

*What has not worked well?*

- Although 5 people with dementia and carers attended on the first Friday in May, on subsequent Fridays fewer came. When the weather was bad no one came. The volunteers and the activities worker staff member had nothing to do on those mornings. This was a waste of staff time and discouraging for volunteers
- Some of the people with dementia came once or twice but not regularly.

- The advice sessions, provided by other organisations include:
- Hambleton & Richmondshire Carers' Centre
- The Volunteer Centre
- Operations Manager, Brentwood Nursing Retirement Home
- Advocacy Service
- Age Concern

These have not been well attended, in spite of frequent advertising, fliers and word of mouth

### *Ways Forward*

A meeting is to be arranged to confirm modifications to the service to ensure its future. Initial ideas for improvements are:

- The Centre should be as the original Project Plan – a Drop-in centre
- Use of the Centre by the “Activities Service” should not be advertised as part of the Centre because it is felt by some volunteers that carers and people with dementia may be put off by feeling that they ‘must’ do activities there, when they may just want to relax and talk.
- Having a staff member there the whole morning has proved unnecessary and wasteful. In future when people with dementia are brought in, the carer support worker will be available on that morning. He will be visiting in the community and will be come to the centre between visits and will stay if needed as the staff member. If the Activities worker would like to bring people with dementia in for activities, this will still be welcomed.
- The volunteers find it difficult to stay till 1pm, no clients have asked for lunch to be provided and the volunteers would prefer the original time of 10-12pm just serving morning refreshments
- Special Friday events will be arranged, i.e.: Strawberry lunch in July, bric a brac sales, coffee mornings etc, which will attract carers and the public to the Centre. Experience gained from running carer’s groups tells us that clients and carers enjoy a day out or a social event more than a ‘therapeutic activity to do with dementia’

## ***Barnsley***

In February 2006, DR and Linda Pattison, the Barnsley branch manager made contact to discuss how the PIP objectives might be applied. In these conversations Linda reflected that the branch was unlikely to be perceived as a rural branch because of the widely held perception of Barnsley as a post-industrial town. In addition, Linda revealed that there was an event being held at Barnsley town Hall in three weeks time at which DR was welcome to talk to those present (branch members, volunteers and health and social care professionals) about the issue of rural inclusion. The planned event was aimed at promoting a new holiday service and presenting an annual review of branch activities. With time limited, DR suggested that he develop a questionnaire based upon exploring issues of rural inclusion and distribute this at the Town Hall meeting.

### *Questionnaire*

DR drafted a short questionnaire with a mixture of open and closed questions which sought the opinions of those connected with the branch regarding the extent to which the branch was meeting the needs of people throughout the Barnsley Metropolitan Area. Linda commented on this draft. At the meeting held on 29<sup>th</sup> March DR spoke to the 40 people who attended about the PIP project and the idea that the Barnsley branch ought to be viewed as a rural branch. The questionnaire, along with a Freepost envelope, was distributed to people as they left the event. A total of 14 questionnaires were completed and returned.

### *Who completed questionnaires?*

*Table 3.4: Respondents*

<i>Type of respondent</i>	<i>Number</i>
Carers	8
Former Carers	1
Managers or Assistant Managers	3
Branch Volunteers	2
<i>Total respondents</i>	14

Two of the people who completed questionnaires were registered disabled. Of the 14 people who completed questionnaires, 8 considered themselves to live in rural areas of

Barnsley while 3 considered themselves to live in urban areas. A further 3 people lived outside the Barnsley MBC area.

#### *Equal access to services?*

People were asked whether or not they thought the Barnsley branch offered people in rural areas equal access to its services. A total of 12 people felt that the branch did while one person felt they did not. One person stated that they did not know.

*Table 3.5: Does the branch offer people in rural areas equal access?*

<i>Response</i>	<i>Number</i>
Yes	12
No	1
Don't know	1
<i>Total</i>	<i>14</i>

#### *Improvements?*

People were asked to describe any specific improvements they would like to see in the Barnsley branch's provision of services to people living in rural areas of Barnsley. The suggestions that were made are quoted below:

*'More posters to let people know about the Society and where the office is'*

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*'Improvements can only be made with more funding, from either central Government or Lottery funding'*

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*'I'm not sure we can make any improvement, other than getting more staff or volunteers who could go on more visits. You have been informed of the dementia cafes which we hope to set up and hopefully these can be held in all areas of the Borough including the 'very' rural areas'*

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*'Meeting places in the local communities on a weekly basis with at least one memory team member in attendance. The venue needs to be agreed by all parties and it should have a social feeling. Maybe meeting in a local working men's club if community centre is booked up'*

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*'Community services within day centres, community centres, council offices offering services locally to make dementia a local concern and more awareness, one day at these places offering services. Or something more permanent. More access to services'*

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*'Barnsley branch have been very, very helpful to [male name] and myself. Our only problem with taking part is transport. The bus transport is not always convenient and we rely more on taxis. I have had mobility problems – but hope soon to be better!'*

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*'Perhaps more social events in outskirts to avoid problem of in-town parking'*

---

*'I believe Barnsley Branch do the best service they can'*

### **Identifying rural areas for new services**

When asked to name any geographical areas of Barnsley MBC area (e.g. towns, villages) where they thought the Alzheimer's Society could do more to support people with dementia and their carers, only one person named specific villages (see below):

*'Cudworth, Monk Bretton, Royston – East side – Meadow Crst [?] area. Pop in clubs and coffee mornings at Warden connected community centres'*

The majority of people completing questionnaires either left this section blank or reiterated that they thought the branch was meeting the needs of everyone.

### **Other ideas for Barnsley branch**

In the final section of the questionnaire people were asked to outline anything else that they felt it would be useful for the Barnsley branch to know about improving its services to people in rural areas. The suggestions that were received are given below.

*'A colleague of mine gave me information about Alzheimer's Society and I think I could pass info on to clients when I go out to do assessments. Any updated info I would be glad to receive'* (Assistant care manager)

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*'We can't attend all meetings so it would be nice to have one locally now and then and get to know the people in our own area with Alzheimer's'* (Carer)

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*'Better funding = more staff'*

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*'By approaching working men's clubs, people who have memory problems and are members, family are able to book the rooms free of charge if the person is a member of the working men's' club'*

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*'The branch are very resourceful themselves. I can only suggest a permanent meeting place (café!) in Barnsley centre – but I know that is very ambitious and beyond their resources. Perhaps a weekly tea dance'*

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*'We have a very good service in Barnsley'*

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*'I think that some form of crèche for emergencies – or emergency carer at home service would be very useful'*

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*'The only thing I can say is, not enough people know about the Branch and the service it has to offer. People are missing out'*

This was a non-representative survey of opinion about rural inclusion amongst those connected with the Alzheimer's Society Barnsley branch. Those who completed the questionnaire overwhelmingly felt that the branch is offering people throughout the branch area equality of access to its services. Alongside this consensus of opinion there were also some potentially useful suggestions for initiatives that the branch might want to explore. These can be summarised as follows:

- *Improve the strategy for publicising services*
- *Recruit more staff/volunteers to conduct an increased number of visits*
- *Arrange weekly meetings in local communities or in the outskirts (e.g. day centres; community centres; working men's clubs)*
- *Consider how transport difficulties may be impacting on take up of services*
- *Support colleagues in the statutory sector to distribute Alzheimer's Society literature*

### *Reflections*

In June 2006, Linda Pattison was asked to reflect on the questionnaire and the results it uncovered. Her views appear below:

*“With reference to Barnsley being considered a rural branch – I did feel initially that we were more an urban branch with some rural areas and I did struggle with how we could get relevant information from people attending the event – I was surprised to see that eight of the 14 who responded considered themselves to live in rural areas of the borough.*

*Obviously it would have been better to have more responses (around 60 people attended the event as you know) but it is good to know that generally people feel we are doing a good job. We always try to take account of any suggestions and ideas put forward – we also undertake an annual quality questionnaire with all our clients – but some suggestions such as recruiting more staff to enable us to increase the amount of support and to hold weekly meetings is subject to finding additional resources – which we certainly would like to do! The information within the report will be discussed with the branch staff team, my service manager and the branch committee to assist when planning developments.*

*No one has asked about the responses to the survey though.*

#### **Section 4: DVD**

A key part of the PIP project is to identify ways of promoting internal partnership within the Alzheimer's Society. One area for improvement identified by the PIP Project Working Group was for better use to be made of the expertise of people with dementia and their carers. The audit of branch services revealed that for people with dementia in particular there is an absence of representation in service provision.

The observation that people with dementia are underrepresented in branch activities, and the acknowledgement that both they and carers have perspectives that are vital to branch activities, led to the planning and development of a DVD for use by branches of the Alzheimer's Society in the Yorkshire Area.

The rationale behind this initiative was that the Working Group felt that within the Yorkshire Area there was a need to identify key spokespeople to talk about the experience of dementia. With such spokespeople, branches would be in a better position to demonstrate the services they are providing and the difference these forms of support can have to people with dementia and their carers. However, it was felt that by capturing the perspectives of people on DVD there was a much better chance of being able to communicate these perspectives to a wider number of people, for example, through learning and development opportunities.

The four people approached to participate in the DVD were chosen from different parts of Yorkshire and on the basis that each had a perspective that would resonate with issues at the heart of the PIP project. A woman from a rural area of Yorkshire, experiencing the early stages of vascular dementia, was identified. An Asian man was identified who was willing to talk about his experience of caring for his wife. Another man was chosen from an urban area, who had vascular dementia and who attended the local Alzheimer's Society art group. A fourth person, a younger woman with dementia was also chosen from an urban area.

All of the participants in the DVD echoed the same message that they wanted to be involved in saying what services are provided. This is best appreciated by watching the DVD and copies of *My Voice* are available from the Yorkshire Area team.

## **Section 5: Inclusion of people from Black and Minority Ethnic communities**

A key objective of the PIP project has been to encourage branches of the Alzheimer's Society in the Yorkshire Area to consider the extent to which they are inclusive of all people with dementia and their carers in their respective branch areas. This objective was explored with specific reference to people from black and minority ethnic communities in the initiatives undertaken at Huddersfield and Bradford branches. The outcomes of these local initiatives have been described in the previous section. In this section some observations are made about wider issues that emerged in the course of the PIP project as a whole and suggestions are made about how consideration of these might help other branches to seek to include more people from black and minority ethnic communities in their services.

### *Monitoring*

It is useful to return to the Audit Form which was sent to all branches in the Yorkshire Area to ask whether branches recorded information about the ethnicity of people who contacted the branch. This revealed that while 16 branches recorded 'first contact' with people with dementia and carers, 5 branches recorded information about their ethnicity (see Section 2). Leaving aside for now the question of how these branches obtained this information, this statistic indicates that at present there are few branches that could state with confidence either the number or proportion of service users that come from black and minority ethnic communities.

This immediately poses a problem for, as the Alzheimer's Society (regionally and nationally) pursues an agenda of inclusiveness, the majority of branches in the Yorkshire Area are unable to provide some 'benchmarking' of their current 'reach' into different ethnic communities. Also, if progress in this objective is to be demonstrated then all branches will need to monitor the ethnicity of service-users.

Just how branches obtain information about the ethnicity of service-users also needs to be considered. A limitation of the PIP Audit Form was that it did not seek an explanation from the 5 branches of how people who contacted them were asked to reveal their ethnicity or how, in a practical sense, this was recorded. Therefore, it is reasonable to suggest that any development of a standardised method for collecting information on ethnicity of service users is informed by the experiences of the 5 branches. Is it the case that these branches have standard protocols which staff members refer to when they

Speak with new service-users? If so, how were these developed? As no standardised method currently appears to exist for branches in the Yorkshire Area it would be useful to discover why each of the 5 branches decided to introduce ethnic monitoring.

*Acknowledging people from BME communities*

During the course of the PIP project some people connected with branches have said – albeit informally – that there were no people from black and minority ethnic communities in their branch areas and, consequently, there were no BME ‘issues’. However, the population statistics for each branch area (Table 5.1) reveal that it is simply wrong for any branch to presume that no people from black and minority ethnic communities live there.

*Table 5.1: Percentage population from minority ('non-white') ethnic groups*

Branch area	% Population from Minority ethnic groups
Barnsley	0.9
Bradford	21.7
Calderdale	7.0
Craven	1.5
Doncaster	2.3
East Riding of Yorkshire	1.2
Hambleton	0.8
Harrogate	1.6
Huddersfield	-*
Hull	2.3
Kirklees	14.4
Leeds	8.2
Richmondshire	1.8
Rotherham	3.1
Ryedale	0.6
Scarborough	1.0
Scunthorpe	2.5**
Selby	0.7
Sheffield	8.8
Wakefield	2.3
York	2.2
Yorkshire and Humberside	6.5

Source: UK Census 2001

\*Figure not available. The figure for Kirklees may be indicative of Huddersfield

\*\*Figure refers to North Lincolnshire

Numbers of these people may indeed be small in real and comparative terms to other more densely populated areas. Yet, if the Alzheimer's Society's attempt to become more inclusive is to be successful then arguably there has to be an acceptance by all branches that it is important to acknowledge and respond to the comparatively small numbers of people from black and minority ethnic communities who might require support from them. By thinking that small numbers equals no numbers, some branches are in danger of perpetuating the difficulties that the current Alzheimer's Society initiative is seeking to overcome.

#### *Individual challenges within collective initiative*

The perception that the Alzheimer's Society is a 'white' organisation is one that was suggested by some participants of the half-day conference hosted by Huddersfield branch. The accuracy of this perception is unknown but it is one that could be responded to if the Alzheimer's Society examined the ethnic profile of its paid staff and volunteers working in Yorkshire Area. However, it is a perception that a number of people within the Alzheimer's Society share, as it was also mentioned by staff attending the PIP Final Project Meeting in York in June and staff attending the Alzheimer's Society Northern Region's 'Everybody's Business' event held in Preston in July.

During the course of the PIP project it has become clear that responsibility for the success of the Alzheimer's Society's aim of becoming more inclusive to people from black and minority communities relies heavily upon the individual paid staff members and volunteers who work in its branches. Some staff members have acknowledged that responding to and initiating contact with people from communities other than their own poses a personal challenge. For example, in discussion groups at the 'Everybody's Business' event some staff members said that, in branches, they had had little experience of contact with people from black and minority ethnic communities. In one example, this lack of experience was accompanied by a very cautious approach to the language that was used to describe people from black and minority ethnic communities. This person perceived that there was a danger of upsetting other participants if she used the 'incorrect' terminology.

Clearly, for some staff, the prospect of offering support to people from black and minority ethnic communities is 'unfamiliar territory' and, perhaps, reflects the fact that there are subtle barriers that exist between people from different ethnic communities in towns and cities in the UK. This is the everyday backdrop to branch activities. As such, it is

suggested that it would be helpful for the Alzheimer's Society to acknowledge the responsibility it is placing on its staff members to change the orientation of branches towards a more inclusive approach whilst, at the same time, the latter live in communities where people from different ethnic groups do not necessarily know each other as well as they could. In short, the drive to improve the inclusiveness of branches seeks to overcome barriers that exist not simply between branches of the Alzheimer's Society and people from black and minority ethnic communities but, more fundamentally, between people in communities in normal everyday life.

The good news is that there are a number of branches in the Yorkshire Area that have a vast amount of experience providing support and services in ethnically mixed areas, such as Bradford and Sheffield. The potential exists for these more experienced branches to share their expertise through new internal partnerships. A forum for branches to do so could be created to offer support to less experienced branches, and the individuals within them who are involved in providing services.

#### *Sharing best practice*

One of the outcomes of the half-day conference at Huddersfield was that the branch manager suggested it would be useful to have a new paid worker in post to coordinate the branch's efforts with people from black and minority ethnic communities. A dedicated worker is, by definition, not someone who is fulfilling this role as a part of wider responsibilities but who is focused entirely on this objective. This model for coordinating branches efforts would seem to offer solutions to some of the problems people described as having prevented them from doing more to encourage greater take up of services amongst people from black and minority ethnic communities. For example, the main problems that came up in conversations there were the lack of time and lack of staff to undertake this role. However, it is unclear what a BME worker would do and how they would do it.

Returning to the Audit Form responses it was reported that only 3 branches provided targeted support to people from black and minority ethnic communities. It would seem sensible for any new initiatives to improve targeted support, such as the employment of a dedicated worker, to be informed by the experiences of branches in the Yorkshire Area where initiatives have or are taking place. This sharing of expertise between branches would, arguably, improve the chances that a new BME worker had of employing effective strategies and setting appropriate targets. This is another area in which a forum for

branches to speak about their experiences of providing services to people from black and minority ethnic communities would prove useful.

### *Partnership and ownership*

The idea that some branches of the Alzheimer's Society have examples of good practice that other branches could learn from informs a final observation. The PIP project has been concerned with both partnership and inclusion. By giving equal prominence to both of these concepts the PIP project encourages a range of partnership arrangements to be considered, in the pursuit of greater inclusiveness. Yet at Leeds branch, predating the PIP project, there had already been the development of a new form of partnership working that, arguably, offers a model for other branches seeking to improve the support offered to people from black and minority ethnic communities.

The Leeds branch had been working with a local African Caribbean community group to offer support to carers and people with dementia. The community group had set up a café for people with memory loss and, working in partnership with the Leeds branch, had arranged for branch staff to ensure that information and advice was available via the café facilitator. The café was not arranged, administered or funded by the Alzheimer's Society but instead was 'owned' by the community group.

This approach represents a possible response to the reported resistance amongst some people from black and ethnic minority communities, highlighted at the Huddersfield conference, to seek support from an organisation that is so explicitly focused on 'Alzheimer's' and 'dementia'. Specific suggestions at this conference were for attention to be paid by the organisation to the need for confidentiality and avoidance of stigma amongst people with dementia and their carers from BME communities. By offering indirect support to people with 'memory problems', via a negotiated partnership with an existing community organisation, the Leeds branch is succeeding in fulfilling its role amongst a group of people who may not otherwise have contact with and support from the Alzheimer's Society.

This model of service provision warrants further scrutiny. It is a model of support that is different from the conventional direct provider-user relationship traditionally employed by branches. Importantly, it is one that is shaped by the realisation that in many branch areas organisations exist to provide support or representation to people from black and minority ethnic communities. These organisations have links into these communities and

are often involved in service delivery. The Leeds branch has recognised this and approached a community organisation to work in partnership to offer support to people with dementia and their carers from that community. This kind of external partnership working is an excellent example of how other branches could make connections with people from black and minority ethnic communities and so this experience needs to be shared.

A Yorkshire Area BME forum would provide an ideal way to share the Leeds branch's experience. However, a relatively straightforward starting point for branches seeking to improve their partnership working in this area must be to map the relevant organisations in their areas, make contact with a representative of each of the organisations and meet to discuss each other's role. In this way, mutual understanding will improve and opportunities can be identified for support to be offered to people who may not otherwise have contact with their local branch of the Alzheimer's Society.

## **Section 6: Discussion**

This report demonstrates the scope of activities that have accompanied the PIP project and the outcomes that have followed from these investigations. The longer term impact of the project will, of course, be judged in time and there are several areas where progress might be measured. This discussion section highlights particular issues that have emerged from the PIP project as a whole with the purpose of stimulating ongoing conversations within the Yorkshire Area Alzheimer's Society about the aims of increased inclusion and partnership.

### ***An unclear picture of potential and actual service use***

During the PIP project the attempts that were made to discover the likely number of people with dementia in the branch areas of the wider Yorkshire Area were clearly problematic. Firstly, PCTs could not systematically provide information on the estimated numbers of people with all or different forms of dementia. Secondly, the estimates that were calculated in this project, by extrapolating from prevalence and population data, were just that: estimates. How are branches supposed to know how many people are their potential service users? There is no easy answer.

The GMC initiative launched this year, to encourage GPs to compile and maintain 'dementia registers' offers a potential route by which branches could, in the near future, learn about the reported incidence of dementia in their areas. The benefit of this type of information is that as incidence data it represents real numbers of people with dementia and an indication of the number of carers too. Of course, the availability of this information relies upon GPs agreeing to undertake this work and it is too early to say what level of interest there is amongst them to do so. It is perhaps useful to point out that during the PIP project one branch in the Yorkshire Area reported that it was actively lobbying their local GPs to introduce the dementia register. This example may be one that other branches wish to follow in order to maximise the likelihood that figures are collected in their local area.

The Audit Form returns also revealed other work that branches could do to give themselves a clearer picture of the numbers of people with dementia and their carers in their areas. While the majority of branches were able to give some indication of the numbers of 'service-users' who had been offered various types of support, there were sufficient 'missing data' and question-marks raised about double-counting to suggest that branches could do more to get to know their clients.

Knowing how many people use services, and who these people are, are of vital importance to branches. Clearly there are some activities where it is easier to 'count' service-users than others. For example, records for day care attendance should be collated as a standard requirement of funding bodies and health and in adherence of safety regulations. The same imperative does not necessarily exist for recording details of people who contact the branch by telephone or in person. The practical work of recording this information may be impeded by the busy-ness of a typical branch office and/or the small number of staff working there. It may also be perceived by staff to be inappropriate, perhaps too invasive, to question too deeply a person who has contacted the branch for support. However, the collection of this and other service-user data may also be prevented by the lack of a coherent policy for doing so within branches and accompanying training and protocols.

The Yorkshire Area has recently devised and introduced a new monthly report form for branches to complete and return. This initiative, informed by the experience of circulating the PIP Audit Form, promises to make the recording of service-user information more systematic across the Yorkshire Area and maintain an emphasis on this important issue in the future. Only by collecting this information carefully and comparing this with other available sources of information on local numbers of people with dementia and their carers can branches know the extent to which they have offered support to those people who might need it. This information will, in turn, be crucial in identifying unmet need and making the case for additional allocation of resources from appropriate funding bodies.

### ***Regular communications***

The audit of branch services revealed that only 8 of the 19 branches had websites and only 3 of these were able to collate information on the numbers of 'hits' they had received. These statistics reveal that branches have some way to go to modernise the way they offer people in branch areas access to information about branch activities. The lack of consistency in the provision of this service suggests that a coordinated effort is required by the Yorkshire Area office to ensure that all branches have websites that are regularly updated and from which statistics about website usage can be obtained. The Audit Form revealed that website development had been undertaken by a variety of personnel and funded by a variety of sources. The fact that fewer than half of branches had websites suggests that there may be insufficient skills and knowledge at branches to be able to start and maintain a website.

It is suggested that the Yorkshire Area office coordinate a learning and development programme with branches to support them to create and then maintain new website services. This should include a review of existing websites provided in the Yorkshire Area and elsewhere to identify 'best practice', and involve consultation with local people with dementia and carers.

A further area of concern in branches' communication services was seen in the provision of branch newsletters. From the audit of branch services it was reported that 4 branches do not produce a newsletter. In addition, there was a great deal of variability in the number of newsletter recipients, ranging from 90 to 1,916. Branch newsletters are a very important means of communicating with a range of stakeholders, from people with dementia and their carers to partnership organisations. The reasons why the 4 branches do not yet provide newsletters need to be established and support provided to them by Yorkshire Area office to do so. In addition, there is a strong case for examining more closely the recipient lists of all branches in the Yorkshire Area to understand how the range in number of recipients can vary so much. In this way it would be possible for branches to consider any gaps that exist in their circulation lists and to explain whether there any other barriers that have prevented them from producing a newsletter.

### ***Services for people with dementia***

As an organisation that is focused on providing support to people with dementia it was notable how few services there are specifically for people with dementia amongst the branches in the Yorkshire Area. Only 8 branches, fewer than half, reported offering support groups to people with dementia. This has to be a concern. The inclusion of people with dementia in branch activities is a crucial form of internal partnership and ways need to be found to improve the current situation.

If branches are not putting people with dementia at the centre of branch activities, alongside carers, branches are failing to meet their needs. They do so because they are not creating opportunities to ask people with dementia what they think about the specific services and support that are offered to them, a form of user-involvement that is commonplace elsewhere. In addition, by failing to include people with dementia in services there is also the consequence that branches are failing to create opportunities for people with dementia to participate more widely in the organisation of branch activities.

This issue is one that is currently being addressed by the Alzheimer's Society Yorkshire Area office and by the National Office. Within the remit of the PIP project it is suggested that branches with experience of providing services to people with dementia in wider branch activities share this expertise with branches with little or no experience.

### ***'Doing' partnership***

When branches were asked to identify other dementia service providers or dementia forums in their areas there was a variable response. Some branches were clearly aware of a great number of such organisations in their areas while others appeared to know of none. The purpose of asking branches was to get a sense of their knowledge of potential partners in the provision of support and services.

The apparent variation could be explained by a number of reasons. Branches in cities will, because of greater numbers of population, have a greater number of potential partner organisations to call upon compared to branches located in rural areas. This is a legitimate reason as it is only possible to name those organisations that exist. However, other reasons might reveal barriers to partnership working that could be overcome. Was it that some branches simply did not know about the range of organisations in their areas that are concerned with dementia care? Was it that branches did not have the information about other organisations in a form that could be easily accessed? Or was it that branches possessed knowledge about other organisations but simply do not have the resources to engage with them? It is an issue that the Yorkshire Area may wish to consider as it may be necessary to offer support to some branches to forge relationships with potential partners.

The example of the Break Free Centre in Leyburn, started by Richmondshire branch in April 2006, may offer a useful template for how branches might seek to forge new service partnerships. The Richmondshire branch identified the need for a new form of support in this rural area and invited other organisations to support their initiative. In doing so the branch drew in, amongst others, the active support of Age Concern, a local advocacy service and a local carers' organisation. As a consequence, the new service was able to offer a much broader range of services to people with dementia and their carers than would have been the case. Also, by engaging in this form of dialogue the branch demonstrated a sense of leadership in dementia care and support which was witnessed by a senior member of social services staff, who accepted the branch's invitation to

attend the meeting to launch the initiative. At a strategic level, and in terms of future funding applications, it can do no harm to the branch to demonstrate its commitment to innovative services for people with dementia and their carers.

The Break Free Service is being evaluated as it progresses and some changes have already been made to seek to improve it. Nevertheless, by actively drawing in the support of other organisations the Richmondshire branch has demonstrated its knowledge of other interested organisations and how partnerships can be created. Other branches with identifiable barriers to partnership working could learn from this experience. More generally, it might be useful for the Yorkshire Area to 'showcase' various examples of good practice in partnership working from amongst its branches. These examples could be in strategic involvement by representation on committees, fostering informal but regular contact with colleagues in the statutory, voluntary and private sectors, or in new service development. What should not be forgotten is that amongst the branches in the Yorkshire Area there are many examples where branches are actively engaged in partnerships with other organisations and these experiences could be shared for the benefit of the organisation as a whole.

An initial set of actions that would improve the situation at those branches where no or few partner organisations were identified would be for them to conduct a local mapping exercise. This piece of research could be conducted simply with a local phone book or by using the local council website to identify organisations. The next step would be for branches to make contact with these organisations and arrange to meet representatives to learn about respective roles and, from the branches' perspective, seek to identify ways of forging partnerships to offer support to people with dementia and their carers in contact with these organisations.

### ***Barriers to change***

The PIP project's work with the 6 Pilot branches demonstrated that staff members are enthusiastic about developing their services in line with the principles of partnership and inclusion. This was clearly seen in the way that branches embraced the opportunities that were created to ask others, be they service users, members of the public or other organisations, about how they perceived the work of the branch. There was a demonstrable openness to the possibility that services might be improved and an appetite to take on board what was said. This attitude bodes well for future initiatives.

Despite this appetite for change it was possible to identify a small number of important barriers that could impede the twin objectives of greater partnership and inclusion. The first of these is the availability of appropriate numbers of staff available to match the heightened expectations for the work to be undertaken by branches that comes with promoting partnership and inclusion. The audit of branch services revealed that many branch activities are provided by small numbers of people – often volunteers, and in some cases by individuals. It has been shown through the PIP project that new partnership and inclusion initiatives take time and commitment on the part of staff to get started – and this commitment has to be ongoing for them to be a success.

For those branches with a small pool of volunteers or small numbers of paid staff care has to be taken to ensure that new activities or objectives are realistic and do not stretch existing resources beyond their capabilities. The Yorkshire Area office could support these and other branches by encouraging them, at the planning stage, to evaluate any new partnership or inclusion initiatives in the light of available resources. This process may result in the targeted recruitment of additional volunteers or applications for funding to appropriate funding bodies for paid staff.

A further barrier to taking forward the inclusion and partnership agenda lies at the level of the individuals who work in branches. The importance of the individual within branches to achieving improvements to the degree of inclusiveness of services was discussed in Section 4 in relation to people from black and minority ethnic communities. The point here was to suggest that the Alzheimer's Society retains an awareness of the context within which individuals are expected to make contact with people from other ethnic communities. This next point about individuals in branches refers to the variation there is between branches in terms of the skills and experience staff members have to pursue the partnership and inclusion agenda.

The audit of branch service activities revealed that branches of the Alzheimer's Society in the Yorkshire Area currently do not share the same management structures, mix of services or staff structures. In short, the skills-mix of branches varies. In addition, branches currently have a range of pre-existing partnership relationships, either formally or informally. Some are well established and others, like the branch itself perhaps, are only just beginning. Therefore branches across the Yorkshire Area are not starting from the same place when it comes to developing partnerships and promoting greater inclusiveness.

As a result of these factors it is likely that the pursuit of improvements to partnership working and inclusiveness will happen in different ways in different branches. People occupying different roles within branches, with more or less time to undertake additional work, with more or less experience will be asked to undertake these new tasks. The Yorkshire Area office appears to have anticipated the impact these differences across branches might have. A meeting held on 20<sup>th</sup> of June 2006 in Hull was attended by representatives of branches from throughout the Yorkshire Area. Part of the business of this meeting was to engage branch representatives in discussions about facets of the PIP project and then encourage these individuals to formulate 'Action Plans' to take back to the branch (see Appendices 4-7). This approach acknowledges the inherent differences between branches and, in effect, asks branches to identify practicable objectives for pursuing a partnership and inclusion agenda. The Action Plans also encouraged branch representatives to identify a timescale for reporting back on the outcomes of their work so the Yorkshire Area office will be able to gauge how realistic the objectives were. It is worth just adding that equipped with an awareness of the differences between branches, the Yorkshire Area office will be able to make judgements about the relative success that branches might have in meeting their objectives.

### ***Innovative dementia support service partnerships***

A further aspect of the PIP project that should be highlighted is the importance of innovation in the creation of inclusive partnerships. Innovation was certainly shown by those branches who took the lead in their local areas to raise questions about the appropriateness of available dementia support. Attention has already been drawn, in the example of Richmondshire branch, to how important it is that branches take the lead in new service development and draw in other organisations. The Huddersfield branch also demonstrated that by taking the lead in talking locally to community representatives about support to people with dementia and their carers from black and minority ethnic communities they created a forum within which dialogue and mutual understanding will continue. Sheffield branch is also in the process of seeking the views of people from minority faith and community groups about the services it provides.

However, the emphasis on innovation here refers to the attempts that have been made by branches to forge 'unusual' partnerships with other organisations to improve the scope of support to people with dementia and their carers. In Section 4 attention was drawn to the efforts of Leeds branch to offer 'indirect support' to those attending a group for people with memory problems run by a local African-Caribbean community group. In addition,

the work of the Bradford branch to collaborate with a local scheme aimed at improving support to people from South Asia has had a subtlety to it that is not present in traditional ideas about how branches should offer support to people with dementia and their carers. Herein lies lessons about the possible direction of partnership working for other branches in the Yorkshire Area.

It is an issue that goes back to the definition of 'partnership working'. It is clearly an important objective of the Alzheimer's Society to work with other agencies to achieve its mission statement of offering support to all people with dementia, their families and friends. The question that arises from the Leeds and Bradford examples is to what degree is it necessary or desirable that branches of the Alzheimer's Society should seek to have exclusive ownership of support and services to people with dementia and their carers? The examples noted above demonstrate that 'hard to reach' groups can be offered support if branches are willing to be flexible and innovative about the ways that this is achieved.

This is not to detract from the more conventional forms of partnership working that is needed. Ways that branches can learn about best practice from other branches within the Yorkshire Area have already been suggested (see above) and the importance of this activity is very high. The point about innovative approaches is that 'the best of both worlds', 'inclusive-partnerships', might only be achievable if branches consider that the delivery of services and support may have to be much more tailored. For example, the organisations representing people from black and minority ethnic communities in areas provide invaluable gateways for branches – and this is the case for all 'representative' organisations.

These organisations have a level of contact with members of their communities that the Alzheimer's Society cannot and perhaps should not seek to replicate. It is arguable that, rather than expecting all people from under-represented groups to realise through better publicity and dialogue that the Alzheimer's Society is their organisation too, branches of the Alzheimer's Society could seek to make contact with people by engaging in 'open' dialogue with other organisations. By doing so, it may be possible to build trust and mutual confidence and identify new, appropriate, opportunities to offer support to people with dementia and their carers from these communities. The result of this kind of approach might be to reshape the nature of some categories of branch service provision but it is perhaps an evolution of ideas about service provision of this nature that will help

bring about improvements to partnership-working and inclusiveness. Echoing a number of points made earlier in this discussion, this kind of service development requires branches of the Alzheimer's Society to share between them the expertise that some have already gained.

## **Section 7: Additional outcomes**

In addition to the outcomes from activities with pilot branches that were described in Section 3, the PIP project has had a number of additional positive. These are directly related to the PIP project and represent evidence of the impact that undertaking the project has had beyond the immediate objectives. These are summarised below:

1. Nicki Dyson, Alzheimer's Society Yorkshire Area Manager, has become an executive member of the Future Years Yorkshire and Humber Regional Forum on Ageing. This occurred as a result of a new partnership initiated with Age Concern in Yorkshire who were also funded by Regional Forum to undertake a similar project to the PIP.
2. A monthly Yorkshire Area branch service activity form has been developed to provide a more effective mechanism for monitoring the services provided by branches in the Yorkshire Area. This service activity form was prompted by and based upon the experience of developing and circulating the PIP Audit Form
3. The national Alzheimer's Society has benefited in terms of the lessons learned from the PIP Audit Form in the development of audit procedures for branches throughout England, Wales and Northern Ireland.
4. Staff members have been involved in considering the provisional findings of the PIP Final Report. A meeting held by Yorkshire Area office in York in June was structured to encourage staff members from all branches in the Yorkshire Area to consider the main findings and make personal Action Plans. This means that all branches have learned directly from the PIP project and are now committed to taking practical steps to improve inclusion and partnership working at a local level (Appendices 4-7).
5. As a direct result of their involvement as PIP pilot branches, two branches have benefited from successful applications for continuation funding from Regional Forum, under their 'Networking' Priority Theme. Huddersfield branch has received funding to attend meetings with organisations representing people from black and minority ethnic communities, produce articles for the local media on this work and make recommendations on future partnership working. Richmondshire branch has been funded to pilot a joint working project with other agencies to provide an activities service for people with dementia in Leyburn, to evaluate this service by consulting service users and developing future partnership working.

## Section 8: Recommendations

The recommendations that are made from the PIP project are outlined below. These recommendations are informed by the various activities described in this report and are aimed at improving the level and quality of partnership working branches undertake and the extent to which branches provide services that are as inclusive as possible to people with dementia, carers and their friends in local communities.

Recommendations are made in three areas of activity: Audit and Information, Internal Partnership, External Partnership and meeting the needs of people from Black and Minority Ethnic Communities.

The recommendations are accompanied by an indication of how each action needs to be achieved, identifies who should take the lead and also suggestions about who else needs to be involved for each recommendation to be acted on successfully.

### 1. AUDIT AND INFORMATION

<i>Recommendation</i>	<i>How achieved?</i>	<i>Who takes lead?</i>	<i>Who else needs to be involved?</i>
<b>1.1. All branches to systematically record number of different service users, periodically shared with Yorkshire Area Office</b>	Agreed protocol Clear allocation of responsibility Learning and development	Yorkshire Area Office	All branches in Yorkshire Area to share experiences
<b>1.2. All branches to create and maintain their own websites</b>	Learning and development into branches to equip staff with appropriate skills Resources for software	Yorkshire Area Office in liaison with central office	All branches in Yorkshire Area
<b>1.3. All branches to produce regular newsletters to Society</b>	Learning and development into branches where	Yorkshire Area Office	All branches in Yorkshire Area

<b>standards and maximise distribution to stakeholders</b>	no newsletter produced. Mapping and inclusion in recipient lists of other local partner organisations		
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## 2. INTERNAL PARTNERSHIP

<i>Recommendation</i>	<i>How achieved?</i>	<i>Who takes lead?</i>	<i>Who else needs to be involved?</i>
<b>2.1. Based on evidence of need develop services so they are provided locally and across the wider Yorkshire area</b>	Feasibility study Involving all stakeholders	Yorkshire Area Office	All branches in Yorkshire Area
<b>2.2. Consultation with branches about low level of provision of services to people with dementia and inclusion of people with dementia in branch activities</b>	Day conference	Yorkshire Area Office	People with dementia All branches in Yorkshire Area

## 3. EXTERNAL PARTNERSHIP

<i>Recommendation</i>	<i>How achieved?</i>	<i>Who takes lead?</i>	<i>Who else needs to be involved?</i>
<b>3.1. Showcasing examples of good practice in partnership working</b>	Promote opportunities for branches to learn about best	Yorkshire Area Office	All branches in Yorkshire Area Partner organisations

by branches in Yorkshire Area	practice		
<b>3.2. Local mapping of other 'partner' organisations that may have access to people with dementia and their carers and contact made with a representative. Information to be periodically shared with Yorkshire Area Office</b>	Consensus amongst branches about appropriate other organisations Phone Book and internet searches	Yorkshire Area Office	All branches in Yorkshire Area Other organisations in each branch area

#### 4. BLACK AND MINORITY ETHNIC COMMUNITIES

<i>Recommendation</i>	<i>How achieved?</i>	<i>Who takes lead?</i>	<i>Who else needs to be involved?</i>
<b>4.1. All branches should systematically, appropriately and sensitively seek to monitor the ethnicity of service-users</b>	Agreed protocol Sharing expertise in Yorkshire Area Learning and Development	Yorkshire Area Office	Branches who do currently monitor ethnicity Local BME community organisations
<b>4.2. Creation of a BME Forum for Yorkshire Area</b>	Regular meetings organised Appropriate support offered to staff members and volunteers	Yorkshire Area Forum	All branches in Yorkshire Area BME representative groups Regional Forum Central office
<b>4.3. Work with partners from</b>	Consultation and development of a	Yorkshire Area Office	National Alzheimer's Society

<b>Black and Minority Ethnic Communities to improve understanding of work done by Alzheimer's Society branches</b>	strategic plan		National Black and Minority Ethnic Community representative organisations
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**Further information:**

For more information on the PIP project please email Nicki Dyson, Alzheimer's Society Yorkshire Area Manager ([NDyson@Alzheimers.org.uk](mailto:NDyson@Alzheimers.org.uk)), or David Reid, Research Fellow, University of Sheffield ([d.reid@sheffield.ac.uk](mailto:d.reid@sheffield.ac.uk)).

**Appendix 1: Population by age cohort in Yorkshire** (Source: UK Census 2001; [www.statistics.gov.uk/census2001/pyramids/pages](http://www.statistics.gov.uk/census2001/pyramids/pages))

	30-34	35-39	40-44	45-49	50-54	55-59	30-59	60-64	65-69	70-74	75-79	80-84	85-89	90+
Barnsley	17391	17215	15470	14257	15335	13272	92940	11286	10186	8960	7632	4782	2525	1223
Bradford	33915	34161	32138	28938	29646	22190	180988	20856	18953	17148	14401	8869	5474	2816
Calderdale	14616	15523	13878	12839	14293	11145	82294	9244	7930	7390	6398	4444	2619	1221
Craven	3261	3829	3909	3678	4330	3652	22659	3093	2869	2630	2267	1573	998	519
Doncaster	20706	22497	20976	18479	20158	16652	119468	14694	13624	12434	10251	6000	3199	1433
East Riding Y.	20345	23594	22443	21484	25648	21079	134593	18291	16724	14570	11912	7768	4561	2300
Hambleton	5561	6706	6364	5897	6845	5807	37180	5040	4276	3753	3005	1989	1092	572
Harrogate	10793	12150	11459	9912	11247	9227	64788	8089	7000	6437	5295	3804	2445	1365
Hull	18454	18470	16303	14656	15481	11243	94607	11104	10796	9472	7958	4958	2870	1283
Kirklees	29893	29416	27185	25038	27437	21629	160598	17972	15554	14289	11952	8164	4564	2321
Leeds	54943	53882	48434	41777	45661	36479	281176	33157	30476	27250	22677	15579	8972	4604
North Lincs	10991	11832	10994	10472	11537	9546	65372	8209	7383	6567	5493	3513	1859	885
NE Lincs	11273	12208	10876	9893	10891	8732	63873	8153	7477	6463	5483	3645	2034	1013
Richmondshire	3587	3499	3186	2833	3290	2802	19197	2437	2091	1813	1405	981	583	283
Rotherham	18790	19218	18185	16050	17666	14992	104901	12995	11318	9724	8190	5341	2837	1247
Ryedale	3080	3638	3545	3439	4091	3629	21422	3187	2893	2614	2101	1454	885	442
Scarborough	6228	7129	7145	6807	8534	7042	42885	6503	5890	5549	4896	3294	2029	1090
Selby	5626	6418	6133	5371	6162	4832	34542	3734	3289	2792	2369	1476	899	438
Sheffield	39542	38744	34096	29885	32281	28249	202797	25181	22609	20325	17614	12869	7206	3433
Wakefield	25180	25189	22539	21099	22558	18417	134982	15774	14109	12266	10563	6693	3487	1514
York	13829	13796	12295	11107	12621	9953	73601	8901	8230	7574	6657	4375	2459	1265
Yorkshire and Humberside	368004	379114	347553	313911	345712	280569	2034863	247900	223677	200020	168519	111571	63597	31267

## Appendix 2: Estimated numbers of people with dementia in selected parts of Alzheimer's Society Yorkshire Area

Area	Ages	Prev	Ages	Prev	Ages	Prev	Ages	Prev	Ages	Prev	Ages	Prev	Ages	Prev	Ages	Prev	Total
	30-59	0.1%	60-64	1.0%	65-69	1.4%	70-74	4.1%	75-79	5.7%	80-84	13%	85-89	21.6%	90+	33.45%	PWD
Barnsley	92940	93	11286	113	10186	143	8960	367	7632	435	4782	622	2525	530	1223	409	2712
Bradford	180988	181	20856	209	18953	265	17148	703	14401	821	8869	1153	5474	1182	2816	942	5456
Calderdale	82294	82	9244	92	7930	111	7390	303	6398	365	4444	578	2619	566	1221	408	2505
Craven	22659	23	3093	31	2869	40	2630	108	2267	129	1573	204	998	216	519	174	925
Doncaster	119468	119	14694	15	13624	191	12434	510	10251	584	6000	780	3199	691	1433	479	3369
East Riding Y.	134593	135	18291	183	16724	234	14570	597	11912	679	7768	1010	4561	985	2300	769	4592
Hambleton	37180	37	5040	50	4276	60	3753	154	3005	171	1989	259	1092	236	572	191	1158
Harrogate	64788	65	8089	81	7000	98	6437	264	5295	302	3804	495	2445	528	1365	457	2290
Hull	94607	95	11104	111	10796	151	9472	388	7958	454	4958	645	2870	620	1283	429	2893
Kirklees	160598	161	17972	180	15554	218	14289	586	11952	681	8164	1061	4564	986	2321	776	4649
Leeds	281176	281	33157	332	30476	427	27250	1117	22677	1293	15579	2025	8972	1938	4604	1540	8953
North Lincs	65372	65	8209	82	7383	103	6567	269	5493	313	3513	457	1859	402	885	296	1987
NE Lincs	63873	64	8153	82	7477	105	6463	265	5483	313	3645	474	2034	439	1013	339	2081
Richmondshire	19197	19	2437	24	2091	29	1813	74	1405	80	981	128	583	126	283	95	575
Ryedale	21422	21	3187	32	2893	41	2614	107	2101	120	1454	189	885	191	442	148	849
Scarborough	42885	43	6503	65	5890	82	5549	228	4896	279	3294	428	2029	438	1090	365	1928
Selby	34542	35	3734	37	3289	46	2792	114	2369	135	1476	192	899	194	438	147	900
Rotherham	104901	105	12995	130	11318	158	9724	399	8190	467	5341	694	2837	613	1247	417	2983
Sheffield	202797	203	25181	252	22609	317	20325	833	17614	1004	12869	1673	7206	1556	3433	1148	6986
Wakefield	134982	135	15774	158	14109	198	12266	503	10563	602	6693	870	3487	753	1514	506	3725
York	73601	74	8901	89	8230	115	7574	311	6657	379	4375	569	2459	531	1265	423	2491
Yorkshire and Humberside	2034863	2034	247900	2479	223677	3131	200020	8201	168519	9606	111571	14504	63597	13737	31267	10459	64151

### Appendix 3: Number of recorded service users of each branch service

Branch	Website	Newsletter	Telephone Support and Advice (TSA)				Support and Advice Helpline (SAH)				Information, Support and Advice (ISA)			
			Carers	PWD	Care Profs	Others	Carers	PWD	Care Profs	Others	Carers	PWD	Care Profs	Others
Barnsley	N/A	304	163	0	0	0	0	0	0	-9	-9	-9	-9	
Bradford	-9	1000	140	0	0	0	0	0	0	53	30	-9	-9	
Calderdale	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	
Craven	4464	350	75	-9	-9	-9	-9	-9	-9	-9	-9	-9	-9	
Doncaster	N/A	250	20	7	19	21	0	0	N/A	N/A	20	7	19	21
East Riding of Yorkshire	-9	30	44	4	20	0	60	4	20	0	60	4	30	0
Hambleton	N/A	N/A	-9	0	0	0	0	0	-9	-9	-9	-9	-9	-9
Huddersfield	-9	350	195	-9	-9	-9	-9	-9	-9	-9	-9	-9	3	-9
Hull	-9	150	8	0	0	0	0	0	0	1	0	0	3	
North Kirklees	N/A	N/A	15	0	3	0	5	0	3	0	10	2	1	0
Leeds	N/A	350	-9	0	0	0	0	-9	-9	-9	208	1	192	0
Richmondshire	250	150	-9	0	0	0	0	-9	-9	-9	23	0	12	94
Rotherham	N/A	300	36	0	0	0	0	0	0	0	12	1	5	0
Ryedale	N/A	140	6	0	0	0	6	0	0	0	25	0	0	0
Scarborough	N/A	100	26	0	0	0	0	0	0	0	0	0	0	0
Scunthorpe	N/A	N/A	3	0	2	0	3	0	2	0	12	0	0	0
Selby and York	N/A	150	20	30	30	30	30	30	30	30	20	1	5	5
Sheffield	304	1916	24	0	0	0	0	0	0	0	24	0	0	0
Wakefield	N/A	745	-9	-9	-9	-9	0	-9	-9	-9	0	0	0	0

### Appendix 3 (continued): Number of recorded service users of each branch service

Branch	SERVICE ACTIVITY												
	Befriending		Day Care Places	Home Care		Lending library	Drop-in				Training		
	Carers	PWD		Carers	PWD		Carers	PWD	Joint Carers and PWD	Others	Carers	PWD	Care Profs
Barnsley	20	N/A	N/A	N/A	N/A	0	N/A	N/A	N/A	N/A	N/A	N/A	35
Bradford	N/A	22	N/A	N/A	N/A	0	3	0	22	0	13	12	280
Calderdale	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Craven	5	5	N/A	N/A	N/A	1	4	0	0	10	5	N/A	9
Doncaster	N/A	25	N/A	N/A	N/A	-9	N/A	N/A	N/A	N/A	N/A	N/A	N/A
East Riding of Yorkshire	-9	9	-9	N/A	N/A	1	N/A	N/A	N/A	N/A	35	N/A	40
Hambleton	N/A	N/A	486	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Huddersfield	N/A	N/A	N/A	N/A	N/A	2	37	19	-9	35	N/A	N/A	-9
Hull	N/A	N/A	N/A	N/A	N/A	N/A	10	2	2	0	80	0	N/A
North Kirklees	N/A	N/A	N/A	N/A	N/A	N/A	0	0	0	10	N/A	N/A	N/A
Leeds	N/A	N/A	3263	-9	26	0	N/A	N/A	N/A	N/A	N/A	N/A	60
Richmondshire	N/A	N/A	168	N/A	N/A	5	5	5	5	5	N/A	N/A	15
Rotherham	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Ryedale	N/A	N/A	N/A	N/A	N/A	6	N/A	N/A	N/A	N/A	26	N/A	N/A
Scarborough	N/A	N/A	N/A	N/A	N/A	N/A	20	0	140	40	28	N/A	N/A
Scunthorpe	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Selby and York	22	N/A	N/A	-9	15	1	6	-9	-9	-9	24	N/A	N/A
Sheffield	3	N/A	-9	-9	-9	5	5	5	5	5	-9	N/A	45
Wakefield	N/A	N/A	N/A	85	85	0	N/A	N/A	N/A	N/A	6	N/A	N/A

### Appendix 3 (continued): Number of recorded service users of each branch service

Branch	Support Groups		Outings	Counselling		Advocacy	Grants		Grants for holidays		Café
	Carers	PWD		Carers	PWD		Carers	PWD	Carers	PWD	
Barnsley	4	6	68	N/A	N/A	0	N/A	N/A	N/A	N/A	N/A
Bradford	22	16	480	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Calderdale	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Craven	14	16	88	N/A	N/A	N/A	3	2	1	-9	25
Doncaster	8	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	
East Riding of Yorkshire	21	4	38	8	4	N/A	N/A	N/A	N/A	N/A	10
Hambleton	19	N/A	-9	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Huddersfield	35	64	250	-9	1	-9	1	1	N/A	N/A	N/A
Hull	33	N/A	95	N/A	N/A	N/A	2	1	0	-9	0
North Kirklees	43	N/A	420	N/A	N/A	N/A	12	0	N/A	N/A	N/A
Leeds	55	-9	N/A	N/A	N/A	N/A	N/A	N/A	95	-9	N/A
Richmondshire	17	N/A	77	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Rotherham	20	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Ryedale	-9	N/A	30	N/A	N/A	15	N/A	N/A	N/A	N/A	N/A
Scarborough	48	32	360	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Scunthorpe	12	-9	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Selby and York	30	N/A	90	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Sheffield	16	N/A	225	N/A	N/A	N/A	8	0	N/A	N/A	50
Wakefield	-9	-9	-9	N/A	N/A	N/A	-9	-9	N/A	N/A	N/A

#### Appendix 4: Summary of Yorkshire Area branch staff PIP Action Plans – Partnership

Actions	Who to involve	Timescale
Explore using students on Social Care courses to become volunteers – experience for their CV	Dearne Valley College to begin with	-
Working with other adjoining branches as much as possible. Statutory bodies, primary care, other voluntary bodies	Local branch managers and service manager	ASAP
Support existing recent developments in this area	All groups	Ongoing
Look at info sharing protocols	SWYMHT, PCT, service user/carer ref group	Next 2 weeks
Identify potential new partnerships in Sheffield, i.e. non-health and social care groups	All branch staff initially via regular staff meetings	June 2007
Closer working with Richmond branch to offer better quality of services	Pam – Richmond, Gill, service manager	Within the coming months
Discuss with branch who our partners should be and establish or re-establish contact	Committee/staff	AOM – October 06
Explore joint working with other Society branches	Service manager/committee/other branches	December 06
Build up relationships with other professionals – involve Age Concern etc. Networking Police training – raising awareness	GPs, statutory services  CPNs, sharing info	Now
To take forward inclusion project working with other organisations		
Local information sharing agreement	Take to local reference groups	Next week
Make sure services are not duplicated	The whole of community	
Quarterly meetings with Age Concern, coffee shop, people	GM/Age Concern	From July

## Appendix 5: Alzheimer's Society Staff PIP Action Plans – Inclusion

Actions	Who to involve	Timescale
Undiagnosed people – people with mental health issues – links with primary care team – working towards continuing involvement with other local organisations in finding people with dementia not already known	Known representatives from other orgs	Current
Include rural areas by leaflet drops	Branch staff (all) Village post office, chapels etc	12 months
Try and establish links across the key ethnic groups in Calderdale	Olinda, Awara, Nazia	1 month
Identify broad categories of potential 'hard to reach' individuals/groups in Sheffield -> identify targets for more detailed activity	Key branch staff – JG, AW, DS, DWL, RG VAS – Planning and Partnership link	December 2006
Listen (we are doing this) One to one clients	DCOs at day centres (already in place) clients, carers	Ongoing
Awareness days at shows	Volunteers	Aug/Sept
Review the findings of the PIP project and incorporate suggestions where possible in action plan Debate the concept of 'inclusion	Committee, staff, service manager	Ongoing
Target areas not accessed before. Think about how people can access information	GP surgeries, warden controlled bungalow complex, shopping malls, mail drop	ongoing
To take forward inclusion project working with other organisations		
Create links for people with dementia who live alone	Whole team, social services, CMHT	Ongoing from now
Better targeted publicity, commitment to start something and endeavour to see it through, take things slowly	Staff and vols (with training)	No timescale
Better publicity for visually handicapped. Hearing loop at meetings egg AOM	Blind/partially sighted society Deaf resources centre and all branch staff	Before Dec Before next AOM

## Appendix 6: Alzheimer's Society Staff PIP Action Plans – Monitoring

Actions	Who to involve	Timescale
Explore possibilities of computer database	Ripon & Harrogate and Hull	-
Finding best way of collecting data	National office staff, branch staff	-
Reviewing procedures for monitoring training	Branch manager	2 months
Investigate possibility of a computerised database	Gail, Kjell, other branches to get ideas (Ripon & Harrogate, Hull)	Within the month
Look at ways of improving monitoring IASS activity to reflect complexity/workload as well as numbers	JG, RG, DS, AW, RJ	September 2006
Complete monthly Audit Form	Staff	ASAP
Monthly branch monitoring form	Branch manager/admin	Monthly
Send comments on monthly report form to area	Myself	End June
Review way we collect data		Ongoing
Monthly reports – training staff, check out good practice	Advertisements – regional working, practise throughout	
Telephone Maria Tuck to come and visit Huddersfield database	Maria Tuck	Next week
Complete new database	Whole team	1 month
Get to grips with monthly monitoring forms. Meeting with York/Selby staff	York/Selby staff	From now onwards

## Appendix 7: Alzheimer's Society Staff PIP Action Plans – Involving people with dementia

Actions	Who to involve	Timescale
Try to include article from person with dementia – their experiences	Users on befriending scheme/dementia café	-
Fundraising activities i.e. pwd doing something Projects i.e. dementia cafés involving social activities for pwd Offering home-based activities service for pwd Taking part in Junior Doctor training scheme – bringing in a speaker who has dementia	Clinical tutor (consultant psychiatrist)	
Include pwd in branch as spokesperson	Branch manager, team, befriender	1 month
Develop the work of 'service user and carer ref group'	Service user and carer group Beechdale Therapy team, day centres, carers project	2 months
Consider how people with dementia can play a bigger role at this year's AGM	JG, ND	October 2006
Identify 2 clients to speak at forthcoming event	Clients from (NO) DC	Later in year
Someone with dementia to committee meeting or planning meeting	PWD	6 months
Use the newsletter to find out who would like to be involved Use 'My Voice' DVD appropriately	Staff	October 2006 Ongoing
Invite PWD to share their views i.e. committee and support groups, act as volunteers	PWD across all age groups	New service – approx 6 months time
Article for Annual review from PWD – who he is, what he's done in his life, how he feels now	PWD plus Janette	Done for July
Case study for local paper during awareness week. Talk at evening to recruit volunteers	Family Support Workers	1 month
Discussions with people with dementia		
Using the DVD with a small group – egg NHS memory group or NHS dementia care	GM, new befriender organiser	By December