A Local Evaluation of Dementia Advisers

(National Demonstrator Site)

Worcestershire

Report for Dementia Adviser Service Implementation Team

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Executive Summary

The Context

In 2009, the National Dementia Strategy for England, Living Well with Dementia (Department of Health, DH, 2009), was launched. The aim of the Strategy is to ensure that significant improvements are made to dementia services across three key areas; namely improved awareness, earlier diagnosis and intervention, and a higher quality of care. It is anticipated that people living with dementia and their families and carers will experience improvements in quality of life, care and service provision as a direct consequence of the achievement of these objectives. The importance of continued intervention following diagnosis is emphasised, as many people experience an ongoing need for information, support and advice as a direct result of the challenges and uncertainty that occurs with the diagnosis, but frequently highlight a lack of support at this crucial phase in their journey. Consequently, objectives 2, 3 and 4 of the strategy address the need for enabling people living with dementia and their families to have appropriate and early access to diagnosis and intervention, and following this easy access to care, support and advice.

Objective 4 of the strategy sets out the need for 'a Dementia Adviser (DA) to facilitate easy access to appropriate care, support and advice for those diagnosed with dementia and their carers' (DH, 2009, p.11). It is proposed that the DA should act as a single point of contact for people living with dementia, providing information and signposting to local services. Their role would therefore be to identify any problems the person with dementia or their carers may be experiencing, and then to facilitate engagement with the specialist services that can best provide them with the help, care and support they need, simply and quickly. However, it is acknowledged in the strategy that there is limited evidence to determine the effectiveness of such a role. Consequently, in mid 2009, the Department of Health launched a call for demonstrator projects to implement and evaluate the effectiveness of the DA role prior to national implementation.

As a direct result of the publication of the national dementia strategy, the West Midlands Darzi Dementia Pathway (Saad, Smith & Rochford, 2008), and local recognition of need, Worcestershire Primary Care Trust, Worcestershire Health and Care NHS Trust (formerly Worcestershire Mental Health Partnership Trust) and Worcestershire Local Authority have jointly identified dementia as a priority. Through local planning and evaluation, it was identified that information, advice and support services were limited in terms of their scope and quality, and that people living with dementia and their families had difficulty accessing the right information at the right time. Consequently, service development priorities were identified, including an Early Intervention Dementia Service. Alongside this, a successful bid to become a demonstrator site for two DA based within two localities in Worcestershire occurred.

The Intervention

The Demonstrator Site for Dementia Advisers (DA) in Worcestershire commenced in December 2009, with national funding until March 2011. The DA were employed by Worcestershire Alzheimer's Society, and aligned with the Worcestershire Early Intervention Dementia Service (EIDS). This was also a new service becoming operational in July 2010 commissioned by NHS Worcestershire and Worcestershire County Council, and provided by Worcestershire Health and Care NHS Trust. The DA offered a service in two localities within Worcestershire whereas EIDS has covered the whole of Worcestershire.

The plan for the demonstrator pilot was that the input of DA would be triggered at the point of diagnosis by the EIDS. Although it was expected that some referrals would come from other local sources, including the Community Mental Health Teams (CMHTs) and via people living with dementia and their families and supporters, the primary referral point was expected to be the EIDS. Therefore, the DA were expected to work with the EIDS in two geographical localities to assist the person with dementia and their family/ supporters to understand the diagnosis and its implications and facilitate access to the care and support needed on their journey. A local evaluation was built in to the original proposal for the pilot of the DA role.

The Evaluation

The overall aim of this evaluation was to deliver a robust assessment of the impact and experience of the role of DA, as well as to determine the skills, facilitators and barriers to the success of the DA role. The following objectives were identified to achieve the aim:

- Compare and contrast the impact and effect of the provision of services following diagnosis with and without a DA;
- Consider the experience of the DA for people living with dementia and their family/ carers;
- Determine the skills, facilitators and barriers to the success of the DA role;
- Enable commissioners to make evidence based decisions regarding the impact of such services and their ongoing financial support;
- Contribute to the national evaluation of the DA programme.

3 main questions were identified in the evaluation

Question 1:

What were the outcomes for people living with dementia, their families and health and care providers?

This involved evaluating the work of the DA against the outcomes below.

For people living with dementia and their families/ supporters using the service:

- Increased understanding of a dementia diagnosis and services that can assist in living well with dementia;
- Increased access to/ uptake of community and specialist services that can help the person live well with dementia;
- Increased coping skills;
- Enable people to make choices about planning for the future at a time when they have better capacity to make key decisions;
- Increased knowledge of who to turn to in a crisis;
- Improved choice and empowerment;
- Increased self esteem/ confidence;
- Improved quality of life (service user's perception);
- Improved quality of life (family member);
- More people living with dementia supported to live at home for longer.

For organisations:

- Increased 'joined up' working between health, social care and third sector organisations
- Improved appropriate use of community services
- Efficient use of health and social care resources

Question 2:

What is the experience of being a DA and what's it like to receive their services?

This involved developing an understanding of the experience of being a DA, the experience of receiving the service and the experience of working alongside the service

Question 3:

Who uses the service, who refers, what interventions occur and what impact does this have on service use?

This involved eliciting data concerning service use, addressing such issues as who uses the service, the nature and type of referral sources, interventions and outcomes.

Methods used to answer the above questions included:

- Recruitment of an intervention and control group of people living with dementia and their families/ supporters;
- Implementation of measures at two time points;
- Semi-structured interviews identified in phase 1 above with service users and their families in receipt of the Dementia Advisory service;
- A semi-structured interview with stakeholders within the areas supported by the DA;

- Monthly, semi-structured interviews with the DA throughout the project;
- Collation of data arising from the DA Client Records System.

The Main Findings

What were the outcomes for people living with dementia, their families and health and care providers?

For People Living with Dementia and their Families
Numbers of people recruited to the evaluation were small, and as a consequence the results can only be viewed as indicators. Nevertheless for people living with dementia and their family members, receiving a service from the DA facilitated some specific outcomes:

- Greater confidence in the availability of support and who to go to if concerns arise, with the feeling of a connection with the DA and trust in them. This was specifically in the context of joint visits to introduce DA with EIDS and where continuity of service was provided, with regular contact with the DA and being linked in to peer support (where the DA also attended);
- Being able to differentiate what the DA would provide from other potential sources of support;
- Having information concerning dementia and a range of issues associated with their needs, including coping with specific challenges experienced;
- The opportunity to plan for the future, including considering financial and care issues;
- The opportunity to consider current financial issues and apply for entitlements;
- Information about local and county wide services such as the dementia cafes, carers sitting vouchers and how to access social care support;
- Feeling supported emotionally.

The knowledge that support was available was not evident for all participants. This lack of confidence in the support available was specifically evident in those who had only experienced contact via telephone on one occasion; where personal contact had not been established; where ongoing contact had not occurred and where the person in receipt of the service was not linked into joined up services such as the Dementia Cafe. This does however need to be considered in the context of a service which was not designed to provide ongoing contact to families, as those indicating this experience were primarily family caregivers.

The receipt of information concerning dementia and a wide range of issues associated with the diagnosis was valued by people who received the service. However it was important to note that the experience could become overwhelming if it was not delivered with sensitivity and due regard to the needs of the person desiring the information. Thus a blanket approach of giving a large amount of information, as experienced by one of the participants without DA was not helpful. Information concerning living well, finances, entitlements and possible future plans were also viewed as helpful.

Participants identified that they had received information concerning local and county wide services available to them and additionally, how to negotiate those services. However there was an absence of discussion from all participants concerning services which may contribute to quality of life, such as those that would enable the person to engage in meaningful activity. It is likely that there are many factors influencing the absence of a discussion concerning possible services that they could access. It seems possible that one of these factors is the lack of provision of opportunities for meaningful engagement which is appropriately structured to meet the needs of people living with dementia and their families. This may also be a contributory factor in the experience of loss and challenges to adjustment in the follow up interviews.

It has not been possible within this evaluation to establish the impact of the service upon self-esteem, quality of life and the person living with dementia being supported to live at home for longer. This has been for two reasons:

- The number of participants receiving and not receiving a DA recruited to the study was much smaller than originally intended;
- The timescale of the evaluation needs to be longer to measure the impact of the DA.

For Organisations

The length of time it has taken to embed the DA and for referrals to be received, points to the considerable effort that has been required of the DA's in order to establish the value of the service and enable other organisations to understand what their role is. Nevertheless, the experience of organisations concerning the DA has been positive, with the following achievements:

- Increased joined up working with EIDS, thus facilitating continuity of provision through the transition of discharge from EIDS;
- Establishment of partnership working with a range of agencies and professionals, including Admiral Nursing, Carer Support Workers, Community Mental Health Team Staff, Consultant Psychiatrists, Liaison Nurses, Social Workers and Town Hall Advisers;
- Enabling people living with dementia and their families to access service appropriately;
- Providing an ongoing contact point for people living with dementia and their families.

Two primary issues have influenced the achievement of outcomes in this regard:

- In Redditch and Bromsgrove, awareness of dementia within the wider community was low; service provision for people living with dementia has been limited and understanding of the potential value of DA was low prior to and in the early period of the delivery of the service;

- The DA's commenced in post 7 months prior to the Early Intervention Dementia Service. As it was intended that their role would be to work with referrals from EIDS plus some self referrals, the different starting points resulted in the DA having to recruit from a wider referral base, including CMHT's and other agencies and professionals where awareness of their role was less well known and understood.

It is suggested that further work needs to be done as there continues to be challenges in regard to:

- Understanding the exact nature of the work of the DA and how they fit into the established care pathways;
- Raising awareness of the DA including more publicity/awareness of the DA role in groups/services and with wider public;
- Ensuring that joint visits with the Early Intervention Dementia Service to introduce the DA occur, given the different bases of the DA;
- Aligning the service with primary care;
- The availability of services to enable people to live well with dementia as this was identified as a significant barrier to the effectiveness of the DA role.

What is the experience of the DA, and what's it like to receive their services?

Being a Dementia Adviser has involved the following key aspects to the role, as described by the DA, the people who have used their services and the stakeholders who have worked alongside them:

- Being alongside the person living with dementia and their family in their journey with dementia, which includes making contact with them on a regular basis, dependent upon their needs;
- Carrying out an assessment of need through which the requirements for information and advice, support and signposting can be determined;
- Providing information and advice which is sensitively tailored to the expressed needs of the person in receipt of the service, which can range from:
    - Information concerning dementia itself;
    - Coping strategies for managing specific issues such as understanding the impact of dementia upon behaviour;
    - Living well with dementia;
    - Future planning;
    - Benefits and entitlements;

    - Signposting, which involves the provision of information about local and county wide services that are available and which can also involve assisting the person to access those services as appropriate to their needs;
    - Providing sensitive assistance with planning for the future, including information about finances.
- Promotion of the role and service, and raising awareness about dementia to individuals, groups and organisations within the local community;
- Networking and developing partnerships with key agencies and individual professionals;
- Developing local knowledge so that signposting activities can be carried out effectively;
- Responsiveness to populations who may be hard to reach;
- Identification of unmet need.

Through interviews with the DA, the people living with dementia and their families and those who work alongside them, plus the data on the topics covered in information giving, it is evident that DA require the following skills, knowledge and personal attributes:

Table i: *Knowledge, Skills and Personal Attributes*

Knowledge	**Skills**	**Personal Attributes**
Dementia (different types)	Ability o work independently	Person Centred Value Base
Psychosocial impact of dementia	Interpersonal and Counselling Skills including active listening	Empathy
Experience of living with dementia	Presentation/ Teaching/ Training skills	Resilience
Coping strategies	Problem solving and creativity	Reflect upon their practice
Local Services	Ability to negotiate relationships with a wide range of people	Selling oneself
Sources of information	Time and self management	In-depth experience of working with people living with dementia and their families
Knowledge of family relationships	Flexible and adaptable in their work with others	Openness and approachability
Having a degree	Having a degree	Enabler
	Ability to work with couples and families who may have competing needs	Assertive and confidence in working with a wide range of organisations and professionals
	Telephone communication skills	Creativity

The experience for the DA in delivering the demonstrator pilot has been a challenging one. A range of barriers and facilitators to the effectiveness of the role have been experienced. The barriers have included:

- The preparedness of the area to receive the DA;

- The receptiveness of other services to the role;
- The length of time it took to receive referrals;
- The emotional experience of providing a service to people with complex and emotionally demanding needs;
- Lack of services to enable people to live well with dementia.

Facilitators which have enabled the DA to overcome these barriers have involved:

- Effective management supervision, peer support and supervision, working together and support from other professionals.
  This has provided the DA with the opportunity to reflect, develop confidence and identity and find alternative solutions in challenging situations. Such provision has additionally been identified by stakeholders as important in fostering resilience and coping with the resistance experienced and the emotional impact of working with the experience of people living with dementia and their families.
- Partnership working.
  The identification and development of relationships with key players, who in turn were able to support the development of the role through referrals and promotion of the DA to others was particularly important in enabling the DA to begin to embed the service within the localities.
- Achieving clarity concerning the nature and boundaries of the role.
  Developing this clarity was facilitated through gaining experience of referrals and thus generating case studies which could be used to describe the work of the DA to potential referring agencies. It also enabled the DA to be clear about the limits of their work as well as where they could afford to be flexible.
- Being outside of Statutory Service Provision.
  Being a non-statutory service was an advantage, as experienced by some of the participants who had received a service as well as stakeholders. However it was also at times viewed as a barrier, as some statutory sector staff did not respect their work as a consequence.
- Preparation of the area.
  One of the localities experienced a greater level of preparation for the work of the DA than the other. This preparation included greater level of awareness; greater understanding of the role; greater presence of Alzheimer's Society and an increased level of services. This had a significant impact upon the speed with which referrals commenced and progression of DA into an integral part of the service in the locality.

In spite of the barriers to the role, it is the experience of the Dementia Advisers, many of those who have received a service from them and many of the stakeholders who have worked alongside them that the service is needed and valued.

Who uses the service, who refers, what interventions occur and what impact does this have on service use?

Data from service use indicates the following:

- A total of 329 referrals were received by the DA during the demonstrator pilot, 190 for Wyre Forest and 139 for Redditch and Bromsgrove;
- Redditch and latterly Bromsgrove took longer to initiate referrals than Wyre Forest and referred consistently lower numbers throughout the pilot;
- Of those referrals:
  - 110 were for people living with dementia
  - 219 were for family members/ supporters
- 71 of the people living with dementia referred were aged 75 and over;
- 65 of the people living with dementia were female, 45 were male;
- 141 were female family members/ supporters and 78 were male.

Further demographic data is incomplete. In particular, the data for ethnicity is recorded only for a small proportion of the referrals. It is therefore difficult to draw any conclusions from this data.

- Where diagnosis was recorded The most common diagnosis was Alzheimer's disease (n.38), followed by Vascular Dementia (n.20) and Mild Cognitive Impairment (n.16) 33 were recorded as other forms of dementia;
- Marital status was incomplete but in those recorded, 20 people living with dementia were married, 69 were single, and in family members/ supporters 13 were single and 128 were married;
- 63% of referrals for family members as carers were spouses, 26% were adult children, 7% were partners;
- Regarding living circumstances, only 48 referrals were recorded, but of those 42 lived in their own home;
- Of the 94 recorded, 20 lived alone and 74 lived with partner/ spouse/ family member.

Regarding the source of referrals, the majority of referrals came from EIDS:

- EIDS 42, persons living with dementia and 55 family members/ supporters;
- CMHT, 40 persons living with dementia and 53 family members/ supporters;
- Voluntary Sector, 10 persons living with dementia and 27 family members/ supporters;
- Carer/ family member, 10 persons living with dementia and 7 family members/ supporters;
- Self referrals, 3 persons living with dementia and 58 family members/ supporters;
- Only 3 referrals were received from Primary Care.

Contacts

- The most common form of contact with recipients of the service was telephone contacts which lasted up to 20 minutes, average 52% of all contacts
- The next most common form of contact was a meeting with the service recipient, which lasted between 55 and 78 minutes and accounted for 27% of all contacts

Figure ii provides a summary of the information topics provided by the DA.

Table ii: *Information topics provided by DA*

Topic	Number of times
Diagnosis	296
Living well	200
Money	162
Health	137
The Future	123
Emotions	109
Legal Decisions	99
Relationships	61

Signposting

- The service most commonly signposted to by DA was the Alzheimer's Society (32%)
- The disability benefits centre was the next most common at 10%
- The access centre for social care referrals was the next most common at 9%

People using the DA Service tend to be mostly, older, white, married people living at home with their partner who is also their carer, although this is based upon data which is incomplete in some aspects. Further information is needed on the extent to which the DA are responding to diversity within the population, and in particular are accessing hard to reach groups such as those living alone and those who are from different ethnic communities within Worcestershire.

The higher number of carers seen by DA may reflect referrals for people whose diagnosis was given some time ago, and/ or who are later in their journey of dementia, but this warrants further exploration/ recording in the database in order to understand the nature of the referrals received by DA, possibly by recording details of the date of diagnosis and length of time experiencing dementia for the person that they care for. This could contribute to a better understanding of the reasons why the service receives more referrals for carers than people living with dementia.

The range of referring groups and organisations suggested that awareness of the DA Service has spread and improved over time. The number of contacts that the DA have with their clients has increased over the months, and is higher than the number of referrals. This reflects the nature of the DA role as they can have multiple contacts with the same client during their journey with dementia, showing that they provide an ongoing service.

The low numbers of signposting activities is consistent with the DA experience of low availability of resources for living well with dementia.

Key Areas for Further Consideration/ Development

For direct work with People Living with Dementia and their Families

While the numbers of people living with dementia in the study are small and not representative, their views provide important pointers in moving forwards with the service. These include:

- A joint visit to introduce the service with EIDS does appear to be an effective strategy as it facilitates a clear understanding of the work of the DA and allows personal contact which creates opportunities to establish trust and confidence in the relationship;
- People who are less likely to re-establish contact, and/ or do not avail themselves of peer support are potentially more likely to lose contact and may benefit from a more assertive and regular form of engagement. Although the DA have regularly maintained contact with some who have used the service, not providing an ongoing service to family members has resulted in a loss of continuity for them and as a consequence for the person living with dementia that they care for. This is likely to become more of a challenge for DA as referrals increase;
- Although defined as a service for people with dementia, referrals have been received for family members consistently. This is likely to reflect the reality of people with dementia who have received a later diagnosis or have received little support and who are less able to engage with the service directly. However it also reflects the DA experience that even for those earlier in the journey of dementia, it is occurring in a relational context, either as couples or as adult children and parents. As remaining at home is predicated on family relationships and care giving, particularly as the journey progresses, is it more appropriate to view DA as responding to people living with dementia, a term which encompasses family members who are also living with it. A clear consciousness can still be maintained on providing a service to the person with the diagnosis in this context, particularly as the interests of both parties are not always compatible;
- Associated with the above issue, it would be beneficial to generate data concerning the characteristics of family members as service recipients, including the diagnosis of the person they are caring for and the date of diagnosis;
- Data concerning the extent to which the service receives referrals for hard to reach and vulnerable populations' would benefit from being consistently recorded. Plans may need

to be considered to ensure that such groups are able to access the service. This includes people with dementia living alone, people from black and minority ethnic groups, younger people with dementia and people who experience dementia in the context of other disabilities which may impact on their ability to access support.

For the delivery of Dementia Adviser Services

- Being based with EIDS, having a close working relationship and a shared understanding of the role appears to maximise opportunities for joined up working to occur;
- Publicity and education concerning the role of the DA continues to be needed within specialist mental health services, primary care and the wider community. This will assist in achieving a greater understanding of the role, therefore clarifying when to refer and enable the role to be embedded into the care pathway;
- Dementia Advisers value firmly embedded structures of management supervision, support and peer supervision in order to address their experiences concerning the delivery of the service and to enable them to develop;
- Ongoing education concerning the core facets of their role, and where possible, for this to be collaborative training with other professionals involved in dementia care would be valuable to the Dementia Advisers;
- Preparation of the locality prior to and during the development of the role is an essential requirement to reduce the time it takes to embed the role and to receive referrals;
- Dementia Advisers need to be proficient in regard to interpersonal skills in order to sensitively respond to the needs experienced by people living with dementia and their families;
- Considering the ways in which the job description, person specification and appointment processes can reflect the range of knowledge, skills and personal attributes required of the Dementia Adviser;
- Considering the boundaries of the work of the Dementia Advisers may become important as they receive more referrals and reach capacity. This would seem to be particularly important to maintain their effectiveness;
- Data concerning promotion of the role, awareness raising and networking might usefully be included in data collection to understand the breadth of work undertaken by Dementia Advisers.

For the Development of Services for People Living with Dementia

- Consideration of how the range of opportunities to meet the needs of people to live well with dementia and their families can be effectively provided with the wider community outside of statutory services, particularly in areas of poor service provision.

This will be essential to address quality of life of people living with dementia and in ensuring the success of the role;

- Awareness raising to challenge stigma and labelling which appears in some services to impact upon their willingness and ability to provide services for people living with dementia.

For Future Evaluation

- It has not been possible to assess some of the outcomes of the service. Future evaluation of the service, which would involve following people living with dementia and their families over time to assess impact upon quality of life, self esteem, coping and ability to remain at home would seem to be an appropriate next step;
- Future evaluation could also consider service use over time, tracking the repeat contacts made with the service and the reasons for this contact, thus developing a deeper understanding of how the contact with Dementia Advisers changes over time and therefore the nature of the work

Full Report

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Chapter 1: Overview of Evaluation

1.1 Introduction

The Demonstrator Site for Dementia Advisers (DA) in Worcestershire commenced in December of 2009, with national funding until March 2011. The DA were employed by Worcestershire Alzheimer's Society, and aligned with the Worcestershire Early Intervention Dementia Service (EIDS). This was also a new service becoming operational in July 2010 commissioned by NHS Worcestershire and Worcestershire County Council, and provided by Worcestershire Health and Care NHS Trust (formerly Worcestershire Mental Health Partnership NHS Trust). The DA offered a service in two localities within Worcestershire whereas EIDS has covered the whole of Worcestershire.

The plan for the demonstrator pilot was that the input of DA would be triggered at the point of diagnosis by the EIDS. Although it was expected that some referrals will come from other local sources, including the Community Mental Health Teams (CMHTs) and via people living with dementia and their families and supporters, the primary referral point was expected to be the EIDS. Therefore, the DA were expected to work with the EIDS in two geographical localities to assist the person with dementia and their family/ supporters to understand the diagnosis and its implications and to facilitate access to the care and support needed on their journey. A local evaluation was built in to the original proposal for the pilot of the DA role.

The overall aim of this evaluation was to deliver a robust assessment of the impact and experience of the role of DA, as well as determining the skills, facilitators and barriers to the success of the DA role. The following objectives were identified to achieve the aim:

- Compare and contrast the impact and effect of the provision of services following diagnosis with and without a DA;
- Consider the experience of the DA for people living with dementia and their family/ carers;
- Determine the skills, facilitators and barriers to the success of the DA role;
- Enable commissioners to make evidence based decisions regarding the impact of such services and their ongoing financial support;
- Contribute to the national evaluation of the DA programme.

A mixed methodology was designed to achieve these objectives, attempting to answer 3 main questions:

Question 1:

What were the outcomes for people living with dementia, their families and health and care providers?

This involved evaluating the work of the DA against the outcomes below.

For people living with dementia and their families/ supporters using the service:

- Increased understanding of a dementia diagnosis and services that can assist in living well with dementia;
- Increased access to/ uptake of community and specialist services that can help the person live well with dementia;
- Increased coping skills;
- Enable people to make choices about planning for the future at a time when they have better capacity to make key decisions;
- Increased knowledge of who to turn to in a crisis;
- Improved choice and empowerment;
- Increased self esteem/ confidence;
- Improved quality of life (service user's perception);
- Improved quality of life (family member);
- More people living with dementia supported to live at home for longer.

For organisations:

- Increased 'joined up' working between health, social care and third sector organisations
- Improved appropriate use of community services
- Efficient use of health and social care resources

Question 2:

What is the experience of being a DA and what's it like to receive their services?

This involved developing an understanding of the experience of being a DA, the experience of receiving the service and the experience of working alongside the service

Question 3:

Who uses the service, who refers, what interventions occur and what impact does this have on service use?

This involved eliciting data concerning service use, addressing such issues as who uses the service, the nature and type of referral sources, interventions and outcomes.

Four questions guided the evaluation structure:

1. Does the addition of the DA to current service provision make more of an impact upon the lives of people living with dementia and their families than current service provision alone?
2. How does the provision of the DA impact upon the journey of dementia for the person and their family?
3. What are the key skills and personal attributes required of a DA?
4. What are the facilitators and barriers to the implementation of DA?

The methods used to achieve answers to these questions included:

- Recruitment of an intervention and control group of people living with dementia and their families/ supporters;
- Implementation of measures at two time points;
- Semi-structured interviews identified in phase 1 above with service users and their families in receipt of the Dementia Advisory service;
- A semi-structured interview with stakeholders within the areas supported by the DA;
- Monthly, semi-structured interviews with the DA throughout the project;
- Collation of data arising from the DA Client Records System.

It was planned in the initial evaluation protocol that the intervention and control groups would number 50 each, (25 for each area the DA's worked in and 25 from two additional areas acting as a control group within Worcestershire). In practice achieving this number was not possible for reasons which are outlined in full later in this report, thus the focus of this evaluation report is primarily on the qualitative data achieved with the results of the measures supplementing the discussion concerning the outcomes identified above.

It had been intended that the evaluation would also include the perspectives of stakeholders who have received referrals from the DA, however the number and type of agencies that people who used the service were signposted on to precluded this form of evaluation.

1.2 Ethical Approval

The research project was submitted through IRAS to the North London Research Ethics Committee 3**,** which was a committee with expertise in reviewing research proposals dealing with adults without capacity to consent. It was provided with a favourable review in September 2010, with subsequent approval given by the local research ethics committee in October 2010.

1.3 Structure of the Report

This report is divided into a number of chapters:

Chapter 2: The Context of the DA evaluation

This chapter covers the context of the evaluation, introducing the background to the development of the role, a brief review of the current literature concerning the needs of people living with dementia and their families/ supporters in regard to information, advice and signposting. Additionally the issues influencing the implementation of this role are considered.

Chapter 3: What it feels like to receive DA or not to receive DA

This chapter outlines the impact and experience for people living with dementia and their families/ supporters in receiving a DA service compared with those who were not in receipt of the service. This section of the report presents the results of the interviews and the results of the measures delivered at 2 different time points to consider such issues as their knowledge of who to gain support from and what is their experience of the support they have received.

Chapter 4: The experience of becoming a DA and service delivery issues

This chapter considers the experience for the DA of becoming and being a DA. The section addresses the core aspects of the role as perceived by the DA, the skills, knowledge and attributes needed to be effective in the role and in addition considers the facilitators and barriers to working effectively. In this section, identifying details of the DA have been changed where ever possible to protect their confidentiality, thus any quotes used do not indicate which DA offered this opinion.

Chapter 5: Health and social care providers perspectives on the DA role in Worcs

This chapter explores the perspectives of stakeholders concerning the DA role. Stakeholders included staff working within EIDS, the Alzheimer's Society, the joint commissioning team, staff working at a senior level who were in a position to influence the development of the role and those who would be referring to the DA as a part of their working practice.

Chapter 6: Who used DA and what were the interventions?

This chapter considers the data concerning service use and the practice of the DA over the time period January 2010 to March 2011.

Chapter 7: Was it a worthwhile investment in improving the service for people living with dementia and their families/ supporters?

This chapter brings together the results of the different aspects of the evaluation in order to consider the 3 main questions identified above. Additionally, this discussion considers whether the service has addressed the outcomes identified in the service specification for people living with dementia, their families and their supporters.

Chapter 8: Key Areas for Further Consideration/ Development

This final chapter provides recommendations concerning the development of the DA service in the future.

Chapter 2: Context of the DA Evaluation

2.1 Background

2.1.1 National Context

Dementia is the biggest health and social challenge facing the developed world. Five percent of people aged 65 and over and 20% of those over 80 have dementia, with over 800,000 in the UK alone, a number that will continue to rise as the age of the population rises, with enormous implications for care provision (Luengo-Fernandez, Leal & Grey, 2010). With this growing ageing population globally the need for ways of providing care for people living with dementia that is humane and person centred throughout the journey is a key concern for politicians, commissioners and care providers.

2.1.2 National Dementia Strategy

In 2009, in recognition of the challenges created by the impact of dementia, the National Dementia Strategy for England, Living Well with Dementia (Department of Health, DH, 2009), was launched. The aim of the Strategy is to ensure that significant improvements are made to dementia services across three key areas; namely improved awareness, earlier diagnosis and intervention, and a higher quality of care. 17 key objectives focused around these three key areas are identified as needing to be implemented at a local level. It is anticipated that people living with dementia and their families and carers will experience improvements in quality of life, care and service provision as a direct consequence of the achievement of these objectives.

In the key area of earlier diagnosis and intervention, the strategy builds upon research highlighting the personal experiences of people living with dementia and their families, who have described difficulties in achieving a diagnosis and in gaining information, knowledge about services, advice and support following diagnosis and throughout their journey with dementia (Beeston, 2009; Husband, 2009; Koppel & Dallos, 2007; Quinn, Clare, Pearce & van Dijkhuizen, 2008; National Audit Office, 2007; Milne & Peet, 2008; Williamson, 2008). The importance of continued intervention following diagnosis is emphasised, as many people experience an ongoing need for information, support and advice as a direct result of the challenges and uncertainty that occurs with the diagnosis, but frequently highlight a lack of support at this crucial phase in their journey (DH, 2009; Lecouturier *et al.*, 2008; Beeston, 2009; Husband, 2009; Quinn *et al.*, 2008; National Audit Office, 2007; Williamson, 2008). Consequently, objectives 2, 3 and 4 of the strategy address the need for enabling people living with dementia and their families to have appropriate and early access to diagnosis and intervention, and following this easy access to care, support and advice. The strategy seeks to achieve these objectives through the provision of Early Intervention Services, which by intervening early in the illness, create opportunities to maximise choice and autonomy, and assist the individual and their family to adapt to the illness and make plans for the future.

Specifically, objective 4 of the strategy sets out the need for ‘a DA to facilitate easy access to appropriate care, support and advice for those diagnosed with dementia and their carers’ (DH, 2009, p.11). It is proposed that DA should act as a single point of contact for people living with dementia, providing information and signposting to local services. Their role would therefore be to identify any problems the person with dementia or their carers may be experiencing, and then to facilitate engagement with the specialist services that can best provide them with the help, care and support they need, simply and quickly. However, it is acknowledged in the strategy that there is limited evidence to determine the effectiveness of such a role. Consequently, in mid 2009, the Department of Health launched a call for demonstrator projects to implement and evaluate the effectiveness of the DA role prior to national implementation.

2.1.3 Local Context

The proportion of the population aged 65 and over in Worcestershire is higher than the average for both the West Midlands and England as a whole. The number of people within this age group is projected to increase by over 70,000 by 2031; again a higher increase than the regional and national averages (Worcestershire County Council, 2011). It is estimated that there are over 7,500 people currently living in Worcestershire with dementia. This includes approximately 160 younger people (under 65), although this figure may be significantly higher due to under-diagnosis of younger people living with dementia (Knapp & Prince, 2007). The number of people living with dementia in Worcestershire is projected to rise by around a third to over 10,000 by 2020. Table 1 shows the current and projected estimated prevalence of dementia in each of the six districts of Worcestershire.

Table 1*: Current and projected estimated prevalence of dementia by district*

	2010	2020
Bromsgrove	1372	1795
Malvern Hills	1376	1776
Redditch	807	1098
Worcester	1049	1262
Wychavon	1695	2307
Wyre Forest	1425	1907

Source: NHS Worcestershire Public Health Information Team (cited in NHS Worcestershire & Worcestershire County Council, 2010, p.9)

2.1.4 Worcestershire Dementia Strategy

As a direct result of the publication of the National Dementia Strategy, the West Midlands Darzi Dementia Pathway (Saad, Smith & Rochford, 2008), and local recognition of need, Worcestershire Primary Care Trust, Worcestershire Health and Care NHS Trust and

Worcestershire Local Authority have jointly identified dementia as a priority. Worcestershire Dementia Strategy (2011-2016) has been developed by NHS Worcestershire and Worcestershire County Council (2011) in order to set out how the aims of the National Dementia Strategy will be achieved locally and how local need will be met. The strategy highlights three key gaps in service delivery, identified during mapping exercises of dementia support services in Worcestershire in 2008 and 2009; namely staff skills and understanding, information advice and support services, and inequity of provision across the county. It was identified that information, advice and support services were limited in terms of their scope and quality, and that people living with dementia and their families had difficulty accessing the right information at the right time. Worcestershire Care Planning Partnership group has therefore commissioned the development of existing services and some new provision for people living with dementia and their families, including an Early Intervention Dementia Service. An aspect of the new service development involved a successful bid to become a demonstrator site for two DA based within two localities in Worcestershire.

2.1.5 The DA Service in Worcestershire

The Worcestershire DA Service (DA) is employed by the local Alzheimer's Society, but is aligned to the Worcestershire Early Intervention Dementia Service (EIDS). The DA also works alongside the developing Admiral Nursing Service in one of the localities. DA input should be triggered at the point of diagnosis by the EIDS. Although it is expected that some referrals will come from other local sources, including the Community Mental Health Teams (CMHTs) and via carers and service users, the EIDS is the primary referral point. A clear requirement of the funding for the DA Service is a robust evaluation of the DA role and its impact.

2.2 Provision of information and advice

2.2.1 Current provision

Research indicates that people living with dementia and their families currently experience difficulty in gaining information about their diagnosis, accessing available services, and obtaining advice and support throughout their life with dementia. For example, discussions with people living with dementia and their carers to inform the National Dementia Strategy for England (DH, 2009) revealed a significant lack of information at and following diagnosis, leaving people living with dementia unsure about what to do next and where to go for support and advice. It was identified that people living with dementia were being discharged from social care and health services as soon as they were in receipt of a care package; however they expressed a need for ongoing support which they could draw upon when they needed it. Similarly, the National Audit Office (2007) found through focus groups and online discussions that people living with dementia felt they had no support following their diagnosis. It was argued that a perceived lack of support at this point can mean that some people living with dementia stop accessing services which may be able to help them. Support following diagnosis is also important for those caring for people living with dementia: Quinn et al. (2008) interviewed 34 spouses and partners of people living with dementia, who reported having to make significant adjustments to their relationship and lives following their partners' diagnosis. The researchers proposed that the difficulties experienced by interviewees were greatly exacerbated by a lack of understanding about the diagnosis and symptoms of dementia, highlighting the importance of supporting family members to develop their knowledge of dementia. Williamson (2008) also explored the experiences of people living with dementia and their carers around diagnosis, and found that the absence of a single point of contact to assist in service navigation along with poor communication between social care and health services made the situation more confusing for those diagnosed and their families. He reported a lack of consistency in information and support provision post-diagnosis, and identified an unmet need for 'timely and accessible' information for people living with dementia and their carers.

2.2.2 Recommendations for future provision

Evidence suggests that people living with dementia and their families perceive continued intervention following diagnosis as vital, citing a need for information, support and advice throughout their journey with dementia and particularly to help them cope with the changes to their lives following diagnosis. Milne and Peet (2008) report that people living with dementia and their families wish for clear information about dementia, current and possible future symptoms, and available support services; as well as greater opportunity to talk about their concerns with professionals. Specifically, they propose that people living with dementia and their carers need access to a 'single point of contact' to address their concerns, gain relevant information, and receive support and advice. Research indicates that this view is shared by people living with dementia and their carers themselves: for example, DH (2009) highlighted the desire of people living with dementia and their carers to have a single point of contact to approach for advice, information and support throughout their journey with dementia. In support of this, during focus groups carried out as part of Williamson's (2008) research, one participant with dementia identified that a 'point of contact at least every couple of months' (p.42) would be helpful so that he would have someone to call on if he experienced any problems. In accordance with this, Williamson (2008) recommended that DA should be recruited to facilitate easier access to services and information and provide a single local point of contact for people living with dementia.

2.3 The role of the DA

2.3.1 Core functions of the role

The core functions of the DA role can be summarised as follows:

- To provide a point of contact for people living with dementia and their carers throughout their life with dementia, including those in traditionally hard to reach groups;
- To provide individually tailored information and advice to people living with dementia and their carers;
- To signpost and facilitate access to specialist services which can provide appropriate additional care and support for people living with dementia and their carers.

(DH, 2009; Alzheimer's Society, 2009)

2.3.2 Skills required for the role

Tsaroucha, Le Mesurier, Benbow and Kingston (2010a, pp.46-49) have developed eight core competencies for the dementia workforce, each of which relates to skills required for the role of DA:

- 'Knowledge/awareness of dementia and dementia related issues' – for example, 'knowledge of local services and contact points' and knowledge of how to 'support and involve' people living with dementia and their carers;
- 'Understanding the behaviours of individuals with dementia' – the 'ability to identify the concerns and priorities of individuals with dementia and their families';
- 'Enriching the life of individuals with dementia and their carers' – for example, 'support[ing] individuals to access and use appropriate services and facilities';
- 'Interaction with individuals with dementia' – for example, effective communication and listening skills;
- 'Interaction with carers/families' – for example, 'listening effectively, showing trust, and... providing appropriate guidance, information and advice';
- 'Dementia worker personal development and self care' – being willing to take opportunities for personal and professional development;
- 'Person Centred Care' – 'demonstrate qualities such as compassion, empathy, encouragement, flexibility, open-mindedness, positive attitude, helpfulness... patience';
- 'Promoting best practice' – the 'ability to communicate and cooperate across professional and organisational boundaries'.

Additionally, Skills for Care/ Skills for Health (2011, p.2) have developed eight Common Core Principles for Supporting People living with dementia; three of which are particularly relevant to the role of DA:

- 'Communicate sensitively to support meaningful interaction' – DA require effective communication skills in order to provide support and information to people living with dementia and their carers, the ability to support those with communication difficulties, and to communicate and build effective relationships with people who are distressed;

- ‘Promote independence and encourage activity’ – for example, the skills to support people living with dementia in accessing appropriate services which will assist in enabling them to cope with the progression of dementia;
- ‘Family members and other carers are valued, respected and supported just like those they care for and are helped to gain access to dementia care advice’ – DA need the skills to work with both the person with dementia and their carer, to signpost carers to sources of information, support and advice, and to enable them to access these services.

People living with dementia and carers themselves have identified that it is critical for professionals working with people living with dementia to be sensitive, caring, supportive, skilled in advocacy, and to have good communication and listening skills (Tsaroucha, Benbow, Merchant & Kingston, 2010b).

2.4 Development and embedding of new roles

As DA work alongside, accept referrals from, and signpost to a range of agencies, it is essential that the new role is fully integrated into existing services to ensure effective multi-agency working. This is particularly important in Worcestershire as the DA Service is aligned to the new Worcestershire Early Intervention Dementia Service; thus two new services have been developed concurrently. The effective development and embedding of new roles within an organisation has been researched by Rosser and Rickaby (2007), who identified that new roles cannot be created in isolation; rather a ‘whole systems approach’ (p.10) to workforce change needs to be taken. They cited education as being important in the development and integration of new roles in order to ensure that staff are confident in their new post, have a clear understanding of their responsibilities, and are aware of the range of agencies and professionals they should be collaborating with. In a report discussing the introduction of new roles within mental health multi-disciplinary teams, DH (2007) identify that difficulties can occur where it has not been considered how new staff will work within existing teams, or how work will be redistributed. It was recommended (DH, 2007) that such planning should take place before new members of staff are recruited, so that once employed in their new post they are clear about their responsibilities and have time to settle into their new role. Existing team members should be made aware of the scope of the new role, and how work will be shared within the team following its introduction.

The introduction of new roles can be a source of potential conflict amongst existing staff, particularly where new and existing roles overlap. Read et al. (2001) recommend that this can be alleviated by ensuring all affected members of staff are made aware of new roles and their purpose and boundaries. Through exploring the development of new roles within the NHS they identified training and education as an issue in the establishment of innovative posts, as due to their very nature relevant training courses are likely to be scarce or non-existent. In-house training developed specifically for the role is unlikely to be accredited and so is generally not transferable; thus having career implications for staff.

Effective collaborative working across a range of agencies is critical to the success of the DA role; however, Secker and Hill (2001) identified that this can be problematic due to information-sharing difficulties and inaccurate perceptions of colleagues' roles and responsibilities. They examined the experiences of mental health staff in a range of community organisations in relation to inter-agency working, and found that staff working for voluntary agencies reported that statutory services were reluctant or unable to share client information with them. Staff believed this was due to a negative perception of voluntary agencies as inexperienced and unprofessional. This issue was compounded by poor collective understanding and agreement of role boundaries: many workers felt they were 'dumped on' by other organisations as they received inappropriate referrals; others were expected to take on responsibilities which they felt were not in their remit. Secker and Hill (2001) recommended that multi-agency training should be developed in order to facilitate an improved collective understanding of the roles and responsibilities of each agency. They also identified a need for local protocols, setting out guidelines for inter-agency working and sharing of information.

Due to current emphasis on the development of an 'informed and effective workforce for people living with dementia' (DH, 2009, p.13), the recent introduction of a variety of new roles in this field (for example, dementia navigators, advisers, pathway co-ordinators, etc.) has led to confusion about the remit of each role (Tsaroucha *et al.*, 2010b). Tsaroucha et al. (2010b) propose that a lack of joined-up thinking and consistency nationally, together with the concurrent development of new roles and responsibilities means that there is a risk of duplication and overlap. They argue that the development of new posts may fragment existing services if not properly integrated, and therefore recommend that integration is addressed as a priority in the implementation of new roles.

Chapter 3: What it feels like to receive or not to receive Dementia Advisers

3.1 Evaluation Methods

This aspect of the evaluation involved mixed methods and recruitment to the study of:

- People living with dementia and their family member/ supporter who had received a DA;
- People living with dementia and their family member/ supporter who were living in an area without a DA.

Informed consent was achieved prior to commencement of the research and additionally, consent was treated as an ongoing process in which the person with dementia and their family member/ supporter were able to withdraw at any point if they felt that they did not want to continue. Following the consent process, each of the participants living with dementia and their family member/ supporter participated in a semi-structured qualitative interview (either individually or together depending upon their wishes) concerning their experience of their current situation, the interventions and support they had received since receiving a diagnosis and where they would go for help in the future.

Additionally, each person living with dementia and their family member/ supporter were asked to complete a number of measures.

3.1.1 The Person Living with Dementia

Rosenberg Self Esteem Scale
This measure is a ten-item Likert scale with items answered on a 4 point scale (strongly agree; agree; disagree; strongly disagree) which is used to assess an individual's self esteem. The possible range of scores for this measure is 0 – 30. It is suggested that scores of 15 – 25 are within the "normal" range and scores lower than 15 suggest low self esteem. (Rosenberg, 1965).

DEMQOL Quality of Life in Dementia Scale
This is a dementia specific measure of quality of life. The possible range of scores for this measure is 28 – 112 with higher scores indicating a higher quality of life and vice versa (Smith *et al.,* 2005).

Duke Social Support Scale
This tool measures multiple dimensions of social support and is a shorter measure than most social support tools, meaning that it is more appropriate for use with older people who may find long measures tiring and confusing. The possible range of scores for this measure is 11 – 33 with lower scores suggesting low satisfaction with current social support and higher scores indicating a greater level of satisfaction. (Koenig *et al.,* 1993).

3.1.2 Family Member (who may also have been the recipient of the service)

COPE Scale
This measure was devised as a screening instrument to identify the support needs of family carers of older people. This measure contains 3 sub-scales: Negative Impact, Positive Value and Quality of Support (Balducci *et al.,* 2008).

- Negative Impact:
    - The possible range of scores for this sub-scale is 7 – 28 with higher scores indicating that the carer is being stressed by the care giving role.
- Positive Value:
    - The possible range of scores for this sub-scale is 4 – 26 with lower scores indicating that the carer is gaining little satisfaction from their care giving role.
- Quality of Support:
    - The possible range of values for this sub-scale is 4 – 26 with lower scores indicating that the carer does not feel supported in their role.

Wellbeing Evaluation Scale
This measure is designed to investigate the well-being of individuals. It is an 18-item measure using a 5 point scale to record responses (strongly agree; mildly agree; neither agree nor disagree; mildly disagree; strongly disagree; [not sure/not applicable – this is also included but does not have a score rating and so is omitted from the overall scoring]). The possible range of scores for this measure is 0 – 72 with higher scores indicating higher overall well-being. General guidelines for analysing scores on the WES are that scores:

- less than 26 are low
- 27 – 40 are low average
- 41 – 54 are high average
- above 55 are high

(Papadopoulos *et al.,* 2011).

Rosenberg Self Esteem Scale
This measure is a ten-item Likert scale with items answered on a 4 point scale (strongly agree; agree; disagree; strongly disagree) which is used to assess an individual's self esteem. The possible range of scores for this measure is 0 – 30. It is suggested that scores of 15 – 25 are within the "normal" range and scores lower than 15 suggest low self esteem. (Rosenberg, 1965).

Neuropsychiatric Inventory (D)
This measure is designed to gain information regarding the presence of psychopathology in patients with brain disorders. It was developed for use with people with dementia. The NPI produces two scores for each person; an overall score and a caregiver distress score. The possible range of scores for this measure is 0 – 120 on the overall score with higher scores indicating more frequent and severe psychopathology. The possible range of scores for caregiver distress is 0 – 60 with higher scores indicating a higher experience of distress as a result of the persons' psychopathology. (Kaufer *et al.,* 1998).

The qualitative interviews and measures were completed over two time points, the first after recent contact with services and the second completed 4 months later.

3.2 Results

It was originally intended that the evaluation would recruit 50 people who had received the DA service (25 from each locality) and 50 people who were living in an area without a DA (from 2 comparable localities). In practice this proved problematical for the following reasons:

- It took a considerable amount of time to achieve ethical approval, thus delaying recruitment;
- DA were appointed and commenced working within the other localities within Worcestershire so recruitment had to be retrospective to identify people who had received a diagnosis prior to the commencement of the new service. One of the consequences of this retrospective recruitment was that it was only possible to contact people by letter, and this combined with the numbers of people who had been given a diagnosis being low, resulted in a poor response rate in these localities;
- One of the DA went on Maternity Leave when recruitment was due to commence and the person appointed to cover her leave was delayed in coming into post.

These difficulties resulted in recruitment achieving a much smaller number of people. The numbers of participants recruited are presented in Table 2.

Table 2: *Participants*

Respondent number	Was the respondent a PLWD ?	Who was the main Family Member/ Supporter	Source of Diagnosis	Did they have a DA	Who received the service?	Nature of contact	Time of Diagnosis	Follow up data
ADS01	Yes	Wife	EIDS	Yes	Both	Joint Visit	Early	Yes
ADS02	No	Adult Child	Cons Psych	Yes	Adult Child	Telephone	Late	Yes
ADS03	Yes	Husband	EIDS	Yes	Both	Joint Visit	Early	Yes
ADS04	No	Adult Child	EIDS	Yes	Adult Child	Telephone	Early	Yes
ADS05	Yes	Husband	Cons Psych	No			Early	No
ADS06	Yes	None	Cons Psych	No			Early	No
ADS07	Yes	Husband	Cons Psych	Yes	Both	Visit	Early	Yes
ADS08	Yes	Wife	EIDS	Yes	Both	Joint Visit	Early	No
ADS09	No	Wife	Cons Psych	No			Late	No
ADS10	No	Adult Child	EIDS	Yes	Adult Child PLWD and Spouse	Joint Visit	Late	No
ADS11	Yes	Husband	EIDS	Yes	Both	Visit	Early	No
ADS12	Yes	Female Friend	Cons Psych	Yes	Both	Visit	Early	No

Key: EIDS= Early Intervention Dementia Service, Cons Psych = Consultant Psychiatrist, PLWD = Person living with dementia

As can be seen from the above table, a total of 12 families were involved in the study, amounting to a total of 8 people living with dementia and 11 family member/ supporters. Of these 11 family member/ supporters, 7 were spouses, 3 were adult children and one was a close friend. Where the participating family did not include a person living with dementia, this was because it was the adult child who was the service recipient of the DA and the family member did not feel it was appropriate to approach the person living with dementia either because they had significant difficulties or because they felt it would cause distress.

- 14 qualitative interviews concerning the experience of the service they had received have been carried out with 12 families affected by dementia at the first time point;
- Three of these families had not had a DA service, although 1 of these did not take part in a qualitative interview.

Follow Up Interviews:

- 6 interviews were completed at follow up

Attrition from the study occurred at follow up for the following reasons:

- 3 families who were not in receipt of DA withdrew due to ill health
- 1 in receipt of DA declined further involvement in the study
- One person with dementia had died and family withdrew as a result
- Unable to make contact with one other family in receipt of a DA

At baseline in three of the interviews, the person with dementia chose to be interviewed together with their family member/ supporter. At follow up, 3 of the 5 interviews involved the person living with dementia being interviewed with their family member/ supporter. Due to the small number of participants, saturation in coding was not achieved, however key messages emerged from the analysis which can provide pointers towards the future development of the work of the DA.

Measures were completed by all but one of the participants living with dementia involved in the study at time point 1 (n.7) and all but one of the family member/ supporters (n. 10). At follow up, measures were completed by n.3 people living with dementia, and by n.5 family members/ supporters. As a consequence of the low numbers of participants it is not possible to provide detailed statistical analysis concerning the results of the measures. Thus this section of the report will focus upon the key themes emerging from the qualitative interviews, and subsequently the results of the measures will be discussed.

3.3 Key Themes emerging from Qualitative Interviews

3.3.1 Time Point One: Baseline

Seven themes were identified at time point 1. These are represented in Table 3.

Table 3: *Key Themes - Baseline Interviews*

Confidence in Support Available
Earlier in the Journey of Dementia
Later in the Journey of Dementia
Connection
Negotiating Services
Working with the family
Lack of Continuity Concerning Experience of Support and Care

Confidence in Support Available

Confidence in knowing who to go to, where to get support from and that support would be available was expressed by particular participants within the interviews. This was evident in those who had experienced both the Early Intervention Dementia Service (EIDS) and the DA Service, specifically where the EIDS staff had worked together with the DA and carried out a joint visit to introduce the DA. These participants were able to identify not only who they would speak to but were able to differentiate the forms of information and support that they would seek from the different services, thus suggesting that they had achieved some understanding of the different roles.

> *"[EIDS Nurse] or [DA], depending on what, whether it was from a nursing point of view which EIDS Nurse is or a practical point of view, which [DA] is" ADS01 FM*
> *"Probably [DA] for her sort of practical aspects, I would" ADS01 PWD*
> *"So if I've got a problem or I want to ask anything, I phone [DA] now, yeah" ADS08 FM and PWD*

Conversely, the participant whose mother received their diagnosis from EIDS, but did not experience a joint visit between EIDS and DA was less clear about the value of the DA and what it could offer them;

> *"So the Alzheimer's society, although they've written to me and I've been send masses of ... information... I don't feel very connected with them" ADS04 FM*

For this participant, the contact from the DA was early on in the setting up of the EIDS and DA service, and their contact from the DA was by telephone, followed up by a written letter. Lesser confidence in support available was also evident in one of the participants who had received their diagnosis from a Consultant Psychiatrist and subsequently were contacted and visited by the DA in the context of a lack of clarity concerning the roles of different professionals.

This lack of confidence in service provision was also evident in those participants who were not in an area where a DA was available;

> *"It would be nice if somebody called in once in a while to ask you how things are, which they don't" ADS09 FM*

or where their original diagnosis was delivered by the Consultant Psychiatrist, but without follow up in regard to services either following diagnosis or until much later in their journey.

> *"To get more advice when the mental health nurse, doctor actually told me and me sister he'd got senile dementia. She should've said he has got senile dementia and here's some booklets or some information if you want to read. But she gave us nothing. She just said he's got senile dementia and it will get worse, and went. Nothing, no back up or nothing" ADS02 FM*

Earlier or Later in the Journey of Dementia (in receipt of DA)
Participants were asked in interviews about the support they had been offered following their diagnosis and who this support had been provided by. Key differences were noted in participants who had received a DA who were earlier in their experience of dementia and their family members, and those later in the journey in regard to the sort of support and interventions they received.

Earlier in the journey:

Information and signposting
Firstly, this was described in regard to accessing services and identifying where to go for those services;

> *"[Identifying] what is available to help" ADS01 PWD*
> *"Well we feel, I feel relieved and quite impressed that there is so much help out there, and you know that it's available as and when we need it… and we've also started this dementia café" ADS01 FM*
> *"DA was more on the physical side, what I, what can be done to help me, what can be done, treating my wife as a full time carer" ADS01 PWD*

Secondly, discussions about advanced planning were identified as an important subject, including where to turn in regard to advance planning;

> *"They've given us support on where to go, go to if we can claim any monies, where to go for wills and grant power of attorney" ADS08 FM*
> *"DA from the Alzheimer's yesterday talking about the… power of attorney, and she was telling me what to expect with [my wife] ADS03 FM*

Thirdly, participants had indicated that they had been able to gain information regarding accessing appropriate financial support and entitlements for example, attendance allowance, and council tax reduction;

> *"I think she sent us a form actually, or got the form sent to us and said if we needed any help with filling it in because it's quite a complicated, well involved, isn't it form" ADS01 FM*

Finally participants indicated that the DA had provided information concerning dementia, exploring such issues as what it is and the impact it has.

While the experience of information giving was largely viewed positively, there were occasions when participants experienced the amount of information given as overwhelming;

> *"So we have had lots of support, paperwork, booklets, information, I mean at, sometimes I have thought I am a bit over-bombarded with it now." ADS08 FM*

Later in the Journey:
The two participants who accessed the DA later in their journey, did so at critical points in living with dementia, including later diagnosis, increased need for care and therefore a need for decision making. Both of these contacts were family members in a care-giving role. These two participants explained that the DA had a role in providing a greater level of information, relating to dementia and coping with changes in behaviour;

> *"She came out, she brought me a file, a folder out with lots of information about you know dementia and then Alzheimer's and I have been on and off the phone to her actually" ADS10 FM*

For one of these participants, this had been the only information she had received since her father had been diagnosed. Both participants indicated that the DA had been an important source of emotional support;

> *"When I've been in bits, DA' been there, she's given me a hell of a lot of support" ADS02 FM*

and in addition that they had helped them to reframe their understanding of the person's behaviour through further developing their knowledge of the reasons for the person's behaviour and developing coping strategies;

> *"He'll always be your Dad, but it's the illness that's … which really helped me to understand it… better than oh me Dad hates me" ADS02 FM*

The participants indicated that they had been provided with information about different resources and benefits available to them as well as assistance in applying for these;

> *"DA gave me the details for those [Alzheimer's Meetings] so I could get in touch to see whether it would be something I'd be interested in going to or taking me Mum"*
> *"DA' sort of … signposted directions in which to go, and … sent me a letter which is like… I've applied for the attendance allowance package, should be getting that prior to the carers package" ADS10 FM*

Finally, one of the participants indicated that the DA has assisted her father in working out individual strategies for coping which included enabling identification of practical solutions;

> *"Because of her incontinence, [the] DA was very practical, she said "Well," she said me Dad's name, you know, it was "how often does that happen?" He went "Oh, well, ah, well, well, it was just this once," and, and "Was there a reason for that?" "Oh well, it was [daughter's] birthday." "Oh well, so it was just a one-off?" "Yeah" "So it doesn't happen too often?" "No" "And you know you can always ring them?" "Yeah, yeah, I know I can always ring them" And she said "And what's the worst that could've, could've happened?" He went "Well, well, a bit of mess" and I, 'cause he's, you know, very immobile, "I couldn't've cleaned up very well." And she just said "Well, you could've put some kitchen roll down, or a towel, and just said look you know, when, when you know, your daughter came round again, look "Ever so sorry, couldn't clean that up, but, you know, can you sort it out?"" And that stuck in my Dad's head." ADS10 FM*

Connection

Underpinning the discussion of these different forms of support received by the participants was the connection that the participants felt they had made with the DA. This in one case involved significant and regular telephone contact, in which the person felt supported to make decisions that were best for her and the family member she cared for. This was also underpinned by the listening skills the DA required, to hear the person's concerns and distress and respond to this.

A further two themes became apparent when exploring the experiences of those in receipt of DA earlier in their journey; working with the family and negotiating services.

Working with the Family

As already identified, some participants identified the DA as an on-going contact for the future. However their discussions also highlighted the necessity of being there for both the person with dementia and the family member. A recurring theme throughout their interviews was the relational context in which the illness was occurring, with couples mentioning how long they had been married and the adaptations they were making together in regard to coping with the illness. Therefore it is not necessarily helpful for them to identify the person with dementia as the sole client of the DA Service.

> *“We are ... aware of her condition, we’ve got the help that we need, which we didn’t know was even existed at one time, and we’re living with it” ADS07*

Negotiating Services

The challenge of negotiating the different forms of service provision, and understanding who provided what level of support was evident in some of the participants’ experiences. In the participants who had experienced a joint visit, the DA appeared to be seen as part of the package of support alongside EIDS. Where distinctions were made, it was that medical issues would be responded to by the Nurse where as practical concerns were dealt with by the DA. The participants seemed to be clear about how to access these services.

However, complications for families who did not experience this combined support were caused by the number of people coming to see the person and uncertainty about their roles;

> *“Doctor put us in … contact with one of her… not a medical person but a social sort of type worker… and she gave us all the information… I can’t recall her name. ..., we’ve had about four or five actually all together” ADS07 FM*

Or by an absence of contact and therefore uncertainty about how to get help should it be needed, which resulted in one person feeling that they needed to go back to EIDS rather than approach the DA;

> *“I think I would probably go back to [EIDS Nurse] first in the dementia service as a signpost” ADS04 FM*

No Access to DA:

For the 2 families who participated in these qualitative interviews who did not have access to DA, the experience appears to be significantly different. A key theme arose from these interviews, which in many respects mirrored the reasons why a DA service was being piloted.

A lack of continuity concerning experience of support and care

For one of the participants, he described that the primary contact he had with services now was through the outpatients clinic however he raised concerns that the delay they had recently experienced in this was not helpful;

> *"The last one was three months ago, in fact ADS05 was due for another visit to …clinic today, or yesterday, and that has now been put back for a further three months, which makes it six months between- interviews, which I'm not happy with... But I don't consider that good enough- that we're losing continuity, whether it's medically required I can't judge but it does cause some concern" ADS05 FM and PWD*

The other participating family had received a diagnosis some time ago, and were now experiencing some difficulties on a day to day basis. In this context, she described that she would seek help from Mental Health Services or from GP. However where this was recently tried, the participant did not feel confident that her concerns would be heard;

> *"Well what I did yesterday, I phoned (CMHT base) I thought I'll ask … cause [they] are the obvious person, "He's not in on Monday, end of conversation. Now I know he's got a deputy, so I suppose if it was bad enough I would've pressed them. In fact I got the number of [the secretary] … but she wasn't in either was she" ADS09 FM*

Both families further emphasised that they would value a contact point/ regular contact/ single point of access;

> *"It would be nice if somebody called in once in a while to ask you how things are, which they don't" ADS09 FM*

Information

It was evident that the 2 families without a DA were resourceful and independent, and were planning for their future. However one couple felt that although they had received a lot of written information following the initial diagnosis, which was in some respects helpful, that this was not tailored to their needs and that they had found it confusing*;*

> *"Following the visit of CMHT Worker in the early stages of assessment, uh, we got, uh, quite a lot of bumpf uh, which uh, confused more than it uh... It was very comprehensive, and it was very well written, but there seemed to be so many organisations essentially doing the same thing, that I'd much prefer, being a systems man, to deal with one organisation who was fully appraised of all the uh, what was going on" ADS05 FM and PWD*

This had resulted in them seeking information from other sources, including the internet and knowledgeable others

> *"Any information that we've felt we need… I've been on to the website… information on Alzheimer's from Wikipedia, the NHS website" ADS05 FM and PWD*
> *"I consulted a daughter who was a Senior Speech Therapist" ADS05 FM and PWD*

3.3.2 Time Point Two: Follow Up

As indicated earlier, the follow up interviews occurred four months after the first interview. The numbers of people living with dementia and their family members participating was smaller than the original sample. All but one of the participants were those who were diagnosed earlier in their experience of dementia. None of the participants who were living in an area without access to a DA participated in this follow up. The key themes identified are listed in Table 4.

Table 4: *Key Themes - Follow Up Interviews*

Adjustment to a difficult journey
Take the Lead
In the loop
Confidence in support available

Adjustment to a difficult journey:
Follow up interviews highlighted the level of adjustment that people living with dementia were experiencing and involved loss of previous abilities and valued roles;

> *"I suppose the trouble was that um, until now I've been used to more or less taking the lead in quite a few areas and um, now, now I can't, and there's nothing I can do about it... But maybe I've, I've turned lazy, become glad of, glad of other people taking the lead now going to meetings and things like this, I, I just don't want to." ADS01 PWD*

And for their family members, adjustment in terms of feeling the need to '*take the lead*'

> *"It hasn't got any worse. You know, I'm at fault at times because I, I more or less take, I take over, I've been told off this morning for doing that... I can't help it, you know what I mean... you want to do as much as you can to help and I do get in the way at times" ADS07 FM*

Even where this was not the pattern in their relationship previously

> *"I think [he] sometimes can't see the wood for the trees, but that's understandable, so I've had to make those decisions, whereas in the past I would've bowed to his better judgement, now I have to insist that when I can see that I am in the right, as I know I am with this, I, I do put my foot down more than I would've done in the past" ADS01 FM*

Participants also referred within this context to the losses they experienced individually and in their relationships with their loved ones;

> *"it's like me dad, but he's not me dad, that's it, he's got two personalities now, which is very hard to accept. And me son was very close to my dad, and he can't understand why he's gone" ADS02 FM*
>
> *"But it, it's very, it's a very difficult situation to be in like we are at the moment. It's very hard, and it can be life destroying really... cause we've been married 53 years and we've been together 56 years haven't we?" ADS03 FM*

In the context of these experiences, participants explored whether they felt supported and knew who to go to in order to gain support.

In the Loop:
4 of the participating families identified that they were able to access support, information and advice should they need it,

"But I can see that there will, I feel there will be a time when I need, when we need perhaps more help, it's a comfort to me to know... that it is out... that there is help there if I need it. That's the main thing, not to feel alone. And I, I feel, you know, had we been down in our old um, you know, had we been down in [previous home town] that we wouldn't have had the support." ADS01 FM

And identified multiple sources of support they could call on should they need help. These sources of assistance included the DA in the majority of the interviews;

"She's very good and I think if I needed her should would be able to sort something out for us" ADS07 PWD and FM
"I know she's always at the end, end of a phone, so I can always phone [DA] if I'm distressed" ADS02 FM

The Early Intervention Dementia Service;

"Well I suppose we'd, we'd ring either [DA] or [EIDS nurse], wouldn't we" ADS01 FM and PWD
"Well the support from EIDS nurse, and that's been great hasn't it? yeah, EIDS nurse has been great" ADS03 PWD and FM

Additionally, participants identified that they would call their general practitioner, who was viewed as an important source of support;

"I would get in touch with our local doctor... I mean she is aware that I'm, I'm registered as a carer in, in the surgery" ADS07 FM

Confidence in the support available

As well as knowing there were sources of support available to the participants, 3 families clearly had continuing confidence in the support available including that the relationship developed with the DA remained strong. This was particularly evident for the participant whose father was more advanced in his journey of dementia who had received ongoing contact with DA through a particularly challenging time. This confidence was also apparent in other participants, who were from the area supported by a DA where there had been continuity in provision. The strength of this relationship appeared to be in part because the DA also attended the local dementia cafe and as a consequence had regular contact with the participants during these meetings;

> *"We did, we met, she was the first person that we met after you'd been diagnosed, and now every month she's at the meetings isn't she?" ADS07 FM and PWD*

Suggesting that these participants experienced continuity in support, information and knowing where to go in order to receive assistance.

However the 2 participating families from the area where there was a gap in provision were less clear about who they would go to for support. For example while one participant mentioned that the DA could be someone they could contact, this was the participant in the first time point who did not feel that they had confidence in the relationship, and in this interview, continued to express concerns about whether they had ongoing support even though this was something they identified they would value;

> *"Now I think the thing that worries me is that in my case, I, I've got sort of connections and I don't feel shy about asking for help, um, but things could run on quite a bit, and you may find yourself a few months, a year or two down the line, in a difficult situation where you then have to contact everybody in, in a panic because things have gone wrong. And perhaps the thing that would've been, would prevent that uh, happening is some kind of review, be it ever so tiny, be it only a telephone call every six months or so to say well, "We saw your Mum so long ago" you know, "you're on our books" as it were, "we're just reviewing where you are. What's the situation? Are things worse? Uh, do you think you need, do we need to do any kind of review? Do we need to come and advise about uh, other services that might be available?" And then I think you would feel you were still in the loop, rather than that you've, you've been doled out your pills" ADS04 FM*

Another couple did not mention the DA as a contact should they feel they needed further help, despite their initial experience with them. They did however indicate that they had regular contact with the Alzheimer's Society through the dementia cafe, and through written information. For both these participants, concerns about the future were evident;

> *"The only thing is, what I'm worried about, see if I've got to go and have an [operation] what happens to [my wife]. And that's my biggest concern and I think if it comes to that I would decline having the [operation]" ADS03 FM*

Neither participant appeared to feel that they were ‘in the loop’. These responses appear to suggest that continuity of provision and being linked in to the wider support network is as important as the nature of the initial contact in establishing a relationship in which participants feel supported. Apart from the Alzheimer’s Cafe, no other services were mentioned in relation to opportunities to improve quality and enjoyment of life by any of the participants in these follow up interviews.

3.4 Summary

The small numbers of people participating in these interviews mean that the results can only provide possible indicators rather than firm conclusions concerning the experience of receiving the service provided by the DA. When comparing the interviews with participants who received the DA compared with those who did not, the results indicate that DA are able to generate confidence in the availability of support and knowing where to go if concerns arise. This is particularly in the context of joint visits between the DA and the EIDS. Joint visits when followed up with regular contact and being linked in to the wider support network, such as peer support (where the DA attends) seemed to be particularly beneficial in maintaining this confidence. In addition, the DA role was more likely to be understood by participants in the context of these joint visits. Where the joint visits and follow up contact did not occur and where contact was initially via telephone, this may have an impact on the experience of confidence in the availability of support.

The aspects of the DA role mentioned by participants included information giving, advanced planning, accessing services including financial support and information regarding dementia early in the experience of dementia. Those participants later in the journey additionally identified emotional support, practical problem solving and a greater depth of information as being provided by the DA. The sensitivity and skill required of the DA was evident in many of the interviews, in for example, being able to assess and provide information appropriately, in knowing when to assist with advanced planning and in understanding the emotional journey for the people who received the service. It is noticeable that the participants did not mention signposting on to services that could provide opportunities to improve quality and enjoyment of life, indeed in the second round of interviews participants were evidently experiencing challenging circumstances. While it is likely that there are many factors influencing this experience, it is nevertheless possible that the lack of provision of opportunities for meaningful engagement has an impact on the success of the role. Services were frequently experienced as being provided to both the person living with dementia and their family member. This was in the context of couples involved in the study defining the experience of dementia as a shared one that they had to cope with together. Thus although the DA role was identified as specifically for the person living with dementia, and their follow up was in this context, in practice those families involved in this research did not make this distinction.

3.5 Results of Measures

Participants were asked to complete a number of measures in the initial and follow up interviews. The total numbers of participants are too small to draw any reliable conclusions from comparisons of those who have received support from DA with those who have not. Additionally, the numbers are too small to draw any reliable conclusions concerning impact over time. Table 5 indicates the results at baseline for the 7 people living with dementia who participated.

Table 5: *Person living with dementia (Baseline)*

Locality	Participant	Scores		
		DEMQOL	Rosenberg	Duke
Redditch & Bromsgrove	ADS07 PWD	104	19	29
	ADS01 PWD	86	23	30
Wyre Forest	ADS03 PWD	91	22	24
	ADS08 PWD	74	9	23
	ADS11 PWD	96	20	26
Wychavon (No DA)	ADS06 PWD	91	19	18
	ADS05 PWD	100	15	29

All participants living with dementia had DEMQOL scores which suggested that they were experiencing a moderate to good quality of life (the range of possible scores is 28- 112). All but one of the participants scored between 15 and 25 on the Rosenberg self-esteem scale suggesting that their self esteem was within normal range. The participant who rated low self esteem on this scale also rated their quality of life lowest in the group. In the Duke Social Support Scale, all but one seemed to experience satisfaction with social support. The participant who indicated lower scores on this measure was the only participant who lived alone.

Table 6 indicates the results for the 10 family members who participated at baseline, 2 of these family members were recipients of the DA. The majority of participants were experiencing a moderate degree of stress as a consequence of their care giving role, and moderate levels of satisfaction. Satisfaction with quality of support was low for some participants; those who had higher scores generally described good family and friendship networks.

At baseline, most family members rated low numbers and frequency of behaviours associated with dementia, and the majority indicated low levels of distress associated with these symptoms.

For all participants, self esteem was within the normal range, and wellbeing scores indicated high average or high levels of wellbeing.

Table 6: *Family Member (Baseline)*

Locality	Participant	COPE Negative Impact	COPE Positive Value	COPE Quality of support	NPI	NPI Distress	Rosenberg	WES
Malvern (No DA)	ADS09 FM	15	12	6	31	13	29	45
Wychavon (No DA)	ADS05 FM	15	13	12	-	-	20	48
Redditch & Bromsgrove	ADS01 FM	12	14	15	10	8	24	57
	ADS02 FM	19	13	8	49	31	16	43
	ADS07 FM	12	16	16	29	15	24	57
	ADS10 FM	11	14	13	15	17	25	60
Wyre Forest	ADS03 FM	16	10	6	11	9	22	45
	ADS04 FM	15	14	13	27	10	30	67
	ADS08 FM	16	12	15	34	22	24	53
	ADS11 FM	9	-	9	11	7	15	52

(- indicates missing data)

Table 7 compares baseline with follow up results for people living with dementia who participated in the second, follow up interviews.

Table 7: *Person Living with Dementia, Comparison Baseline and Follow Up Scores*

Locality	Participant	Scores baseline/follow-up		
		DEMQOL	Rosenberg	Duke
Redditch & Bromsgrove	ADS07 PWD	104/108	19/29	29/29
	ADS01 PWD	86/83	23/14	30/23
Wyre Forest	ADS03 PWD	91/84	22/19	24/20

Participant ADS01 PWD experienced lower levels of social support and lower levels of self esteem at follow up, this was in context of their qualitative interview at follow up in which they expressed sadness at loss of valued functions. ADS07 PWD was experiencing higher levels of self esteem. ADS03 PWD experienced slightly lower scores, in interview it was identified that the participant had been unwell and was also experiencing a loss of valued friendships.

Table 8 compares baseline results with follow up interviews for family members.

Table 8: *Family Member Comparison Baseline and Follow Up Scores*

Locality	Participant	Scores baseline/follow-up						
		COPE Negative Impact	COPE Positive Value	COPE Quality of support	NPI	NPI Distress	WES	Rosenberg
Redditch & Bromsgrove	ADS01 FM	12/12	14/14	15/15	10/18	8/11	57/60	24/20
	ADS02 FM	19/15	13/13	8/11	49/29	31/19	43/32	16/13
	ADS07 FM	12/13	16/15	16/14	29/45	15/24	57/65	24/27
Wyre Forest	ADS03 FM	16/19	10/14	6/9	11/-	9/-	45/-	22/16
	ADS04 FM	15/15	14/11	13/11	27/16	10/9	67/56	30/25

(- indicates missing data)

ADS01 FM indicated the same scores on the COPE as their baseline measures but slightly higher on levels of behaviour (NPI D) and a slight increase in associated distress. At interview, this participant indicated that her husband's behaviour had changed and that she had to do more for him. Self esteem and well being remained within the range indicated at baseline interview.

ADS02 FM seemed to be experiencing less stress associated with care giving, which correlates with her perception expressed at interview that her father is now well cared for in a care home. She experienced the same level of satisfaction with her role and higher levels of satisfaction with support that she receives. She experiences lower levels of behaviour and distress associated with this, again possibly being linked to her father's admission to care. However scores indicate low self esteem and lower wellbeing.

ADS07 FM has similar scores at follow up concerning experience of caring, and indicates higher levels of behaviour and their frequency and higher levels of associated distress. However self esteem and wellbeing remained at a similar level.

ADS03 FM has slightly higher experience of stress, satisfaction and quality of support in their care giving, but is experiencing lower levels of self esteem although this is still within normal range.

ADS04 FM experienced similar levels of stress in relation to their caregiving role, slightly lower positive value and lower experience of support. The number of behaviours and frequency was slightly reduced and distress remains low, which may indicate that the person is coping better with the demands of care giving. Self esteem was still within normal range, well being was also still within the high scoring range.

3.6 Summary

As indicated in the introduction to this section, results from the measures cannot be subjected to statistical analysis due to the low numbers participating in the evaluation; therefore reliable conclusions cannot be made. People living with dementia at the baseline interview showed moderate to good quality of life, and the majority experienced normal self esteem. Most were satisfied with the level of support they received, the only person who wasn't satisfied, lived alone.

The family members also had high average or high levels of wellbeing and normal self esteem. The majority experienced a degree of negative impact of their care giving role, which is consistent with recent literature concerning the experience of care giving (Quinn *et al*., 2008). However the majority also experienced a degree of satisfaction with care giving. Some family members indicated that their satisfaction with the quality of support they received was low.

Family members indicated that the person they supported had low levels of behaviours associated with dementia, as one might expect for people earlier in the experience of dementia, and rated the distress they experienced at these behaviours as generally low.

Some small changes were evident at follow up for the persons living with dementia and their family member; however it is not possible to comment upon these differences due to the small numbers participating and the small differences predominantly noted.

Chapter 4: Becoming and Being a DA

4.1 Evaluation Methods

The experiences of the DA in delivering the service were sought through semi-structured interviews from December 2009 through to April 2011. In total, 16 interviews were completed, the majority of which involved interviews in which the DA were seen together. The questions focused upon what activities they had carried out over the previous month, their experience of carrying out these activities, their understanding of the role, the facilitators and barriers to enabling them to function in the role.

Data obtained from the interviews was transcribed and anonymised. Analysis was carried out using line by line thematic analysis (Ryan & Bernard, 2003; Braun & Clarke, 2006). Coding was subjected to checking by a researcher not involved in the data collection. Transcripts were coded to develop major themes and sub themes, employing both inductive analysis (derived from the experience of the participants) and deductive analysis (derived from literature and the experience of the researcher). Analysis considered the experience over time as well as the common themes arising from all of the interviews.

4.2 Results

The results section will first consider how the DA have perceived their role, and will explore the way in which the service was delivered. This section will also consider who the DA service is for. Secondly, the skills, knowledge and attributes required of a DA will be explored, in relation to their direct work with people living with dementia and their families and in regard to their working relationships with professionals and other agencies. Thirdly, the intra-personal, interpersonal and organisational facilitators and barriers to effective working will be explored.

4.3 The Role of the DA

DA identified a number of key aspects of their role, which are shown in Table 9.

Table 9: *The role of the DA*

Alongside through the Journey
Assessment
Education
Information and advice
Signposting
Networking
Working with different populations

Alongside through the Journey

As was identified earlier, one of the key characteristics of the DA role is to provide a contact throughout the journey of dementia. This was a common theme identified throughout the Advisers' discussions concerning their role and recognised in the National Dementia Strategy (2009) as something people living with dementia and their families wanted and needed;

> *"I think we always said 'if ever you need to talk, we're at the end of the phone, contact us whenever', I think it is part of the role to be there ...you're there for the long term"*

The DA highlighted the importance of developing trust at the initial contact in order for this ongoing relationship to be secured;

> *"I have had a few people phone me up, these are people who I have met before, then probably about 2-3 months later, they're phoning me now saying 'could you come out and see us again', that helps me to feel confident because they obviously trust that I know what I am talking about, and I helped them before and they have another issue and feel confident that they can phone me up"*

However as implied in the above quote, the way in which this relationship was developed in order that the person felt able to make contact again was significant. The DA talked about building the relationship with people using the service through initial joint visits with EIDS, and in this example highlighted how their working practice had been influenced by the working relationship they had established with the EIDS nurse;

> *"[The EIDS Nurse] felt at the very beginning that giving a leaflet would never be enough. She felt that wouldn't work, because you're always going to get people that wouldn't pick up the phone for whatever reason it might be really... And so she'd rather do them in joint visits you know... I think it builds a better relationship when [she's] there. You know, so that works very well."*

The DA reinforced that personal contact was more likely to establish this relationship than telephone contact;

> *"With some they only, especially phone conversation ones, they tend to be less likely to come back in to the service I think".*
>
> *"I think when you've [met] them on a personal level, they tend to bring, they're the ones that tend to re-contact more".*

They also discussed the process through which they reinforced their availability and accessibility which included writing to the person using the service following their initial contact;

> *"Usually when I do the first visit, I... give it a weeks, and on a quiet day I... write, and I go over and clarify what we talked about in the visit and enclose any information I said I was going to give"*

Or following up with a phone call to reinforce their availability and how to contact them should they feel that they need it. Establishing the relationship also involved recognising that not all people who use the service would make contact if they were experiencing a crisis, and as a consequence the DA additionally reinforced that they would need to make regular contact with people who had used the service but had not got back in touch themselves.

Being alongside the person through the journey also highlighted some particular needs for the DA in terms of supervision and support. One of the DA summed their experience up;

> *"But you know it's never gonna be enough, and that's the difficult part. For that very short little period, you know it is a 24/7 job. So, I think, without, probably without the skills that I learnt when I was training in my counselling, and my, my years [working in this area] and working with people with dementia and trying to understand the person, I think without that I couldn't have done it, couldn't have done the job. ... And I've learnt a lot of it as well about the emotional side of it, is I've also learnt what a heavy job it can be. It comes with a lot, a lot of sadness. You go home sometimes and, and I found that and I, that's more so in this job than in, in any other job I've done".*

This highlights the need for appropriate support and supervision to maintain a stance of alongside the person through their journey.

Assessment

A core function of the role as perceived by the DA was that of assessment. This involved exploring the needs and wishes of the person and their family. Additionally assessment involved considering what help might be needed, the services that might respond to their needs, the entitlements they may be eligible for and the information required. This assessment occurred in their initial and subsequent meetings with the person or family that they are seeing;

> *"You're picking up on everything when you first meet, meet them anyway. You're picking up on, you know, are they getting their benefits, their entitlements, have they thought about the future, where are they in their diagnosis. So it was about, you know, how they were feeling and, is there anything they're struggling with, did they need. So I was trying, you try and pick out what it is you can help with. Are they isolated, are you looking about, you know, is this person going to benefit from some peer support, you know? Are they going to benefit from being more involved, be getting out into the community more? Is it more on a personal level? Coping strategies, is it about the memory? Are they at a stage where some of the strategies could be helping, the whiteboards, the diaries, the calendars? Are they past that stage? Are you looking at assistive technology now? You know, little reminders and... You know, have they got their ID card in case they go out?"*

As can be seen from the above quote, this assessment process demanded breadth and depth of knowledge in the DA, concerning dementia, available resources, and the experience for the person living with dementia and their family. Additionally the DA needed a high level of interpersonal skills to manage this assessment in a way that allowed the persons views to be heard and respected;

> *"He don't know me some days" and you're listening to all that as well. So you're trying to think of little, you know, ways of 'em coping really... Or they might just want to get it off their chest. So you do a lot of listening as well"*

Such skills were also needed to manage situations where competing needs were in evidence, for example with meetings with more than one person in the family;

> *"Especially if there's more than one person in the room, because all their needs were different ... I met a family yesterday that had, and I was trying to pick out where the Mum was, where the Dad was and where the daughter was, 'cause they was all at different, different stages really It's also about picking up on, they'll have different worries"*

These examples show that the DA require a range of interpersonal skills associated with awareness of their interactions and the ability to reflect to a degree that enabled them to appropriately assess the needs of people living with dementia and family members.

Promotion of the Role

The DA highlighted promotion of the role as a key aspect of their work. This began very early in the development of the service, and involved informing others about the key aspects of the role of the DA and what they could provide, often in formal presentations as well as more informally to groups of people;

> *"I did a talk at the Older Persons Forum in [area] that was busy, that was a good session. And the carers, I did the Carers Support before that, and now they've contacted me again to ask me if I'd do a talk at the older Asian Men's Support".*

Promoting the role involved networking with many different professionals and agencies, including carers groups, CMHT's, Social Work teams, Admiral Nursing, and Town Hall Customer Advisers. Inevitably these meetings to promote the role were also opportunities to raise awareness around dementia with some organisations or groups that wish to know more;

> *"When I went to meet the town hall, a lot of them asked the same thing and somebody said 'there is about 3 different types isn't there?' and we elaborated more on that then, 'you can't prevent it though can you?', well yes there are types of dementia you can prevent. We talked about the younger generation, because there are big pockets of young people within [work area] and we talked about Korsakov's and drink, a healthier living for vascular dementia, so it was really interesting the town hall meeting. We talked about all sorts of things really – it was very positive"*

Promotion of the role at times involved providing a justification for the service and additionally for their role in that service;

> *"If I, if I'm at a meeting with lots of professionals and I make a suggestion or whatever, and it's like "Oh what do you do?" "I'm a Dementia Adviser." "What's your background?" It's almost like people are saying "And what qualifies you to, to do this?""*

The DA highlighted that having the necessary qualifications was important in enabling others to respect their opinions;

> *"I think you do need a degree. If we had gone into places and people had said 'well what qualifies you to do that?', you have to be able to back it up, and if you say you have an NVQ level 3, people just won't take you seriously – which is quite sad really – but we are judged quite often"*

Promotion of the role has continued to be an important facet of the work of the DA throughout the period of the evaluation, with some degree of activity mentioned in all but one of the interviews with the DA.

Information and Advice

The provision of Information and Advice is highlighted within the National Dementia Strategy as a key component of the role of DA. This is emphasised by the DA in their interviews, as is the range of topics that they are asked about including:

Health and Well-being

> *"The person that I spoke to yesterday that I'm seeing next week is a carer, and he wanted quite a lot of information about his mum, she has just stopped eating"*
> *"I had a lady walk in today to ask me about sort of specialised dementia holidays"*

Work and Driving

> *"Couple of people in early diagnosis who were still working, still driving ... She was saying 'I don't know if he should give up work'"*

Information about their diagnosis

> *"If someone has received a diagnosis and they're not really sure what it means, just to explain it to them and give them reading materials, talk through any worries they have, give them time to asks questions"*

Benefits and Entitlements

> *"Every benefit that they're entitled to, because you're still coming across people who didn't realise they could have had a reduction on their council tax, or to ask in a higher rate in their attendance allowance, they need to look at all that because that money can go towards purchasing services"*

Planning for the future

"What they say, what they... I met a couple this week on Monday I went to meet them, who's just been recently diagnosed and they talked about, they're saying after Christmas and in the New Year they're going to start talking about the power of attorney and legal decisions, the bank account, all that side of it really. And, and we discussed about you know when the time comes about the benefits and that"

As with assessment, the sensitivity and skills required of the DA are evident in this aspect of their role. The DA highlighted that not everyone knows what information they want, and that this requires sensitivity to ask the right questions and not give out information without being sure of the readiness of the person to hear it;

"We have a particular book that we both feel is a brilliant book, it goes through the types of dementia, the types of dementia, behaviour, hallucinations, understanding – it is brilliant but it will only suit certain people because it can go into a lot of depth and it isn't for everybody. I gave mine away because I met the ideal person it would suit, and then we're asking 'can we have some more' ... but at the end of the day it won't be for everyone. Until you have had a conversation and listened to their story and what they're saying you'll think 'this book is for that person' because it is all in one cover, but it does touch on death and it does touch on palliative care, there are some people that don't want to know that, so it is about sussing that out and I thought this person would be ideal and this book had everything in they needed to know. But there are some people you meet and you think 'I'm not giving them that one, that one isn't for them' because they're not at the stage where they can deal with the downside of things".

This was particularly evident in discussions concerning advanced planning. The DA highlighted that not everyone wants to know or plan for the future, and that it was very important to go with their pace;

"But it's about being tentative about future planning and I think it's something we've talked about with [consultant] before. A lot of people don't want to think that far ahead. You let them lead it really".

Furthermore, the DA also indicated that it is important to achieve the right balance in providing information and advice, and that there was the risk that the amount of information could be overwhelming;

> *"Sometimes it can be a lot of information and you come away thinking 'I hope I haven't overwhelmed them', because you may have covered that many subjects in an hour and you've thought you've gone through benefits.... I met a lady the other week whose husband is my first early onset and ... we went over that many things, so I did write, and photocopied a couple of things I thought would help. I think at the time her head was already full, so I always write, and put any information in and say 'don't forget, if you ever need to contact me I will be there, if I don't hear from you I will give you a ring in a couple of weeks then just to ask how things are'".*

Information giving also required creativity to offer explanations that were tailored to the person's understanding, thus the DA talked about using different ways of explaining about dementia;

> *"I mean we've got all the books and the information and the sheets, but there are some instances where something like a visual card is what we need. ... I'm going to try and find some sort of a clear picture for a more visual understanding, and maybe laminate it and take it as part of my toolkit... The other week I met an old gentleman who's in his 90's and quite frail, ...And um, I was trying to explain to him about Alzheimer's and I put me hand in me bag and I had a bunch of elastic bands, so I put them in me hand and I sort of said to him "You can imagine these elastic bands and say your thoughts are trying to get through all these..." so I tried to explain it like that to him. And he said "Oh yeah" I said "Well you know if they gets in these tangles that things can't come through" and I thought, "See, a picture would've been good for him really.""*

The nature of the information and advice offered by the DA also varied in terms of whether the person receiving the service was referred earlier or later in the journey. The level of information and advice for people referred earlier in the journey was more likely to involve information concerning dementia, living well with dementia, including resources and sources of support, planning for the future, and benefits/ entitlements;

> *"They're still early, there is no crisis, they're coping, they're doing ok, they want to know the answer to the questions, they want to know what's out there, they still want to know more about their diagnosis, you know, the booklets have gone down very well"*

The DA described working within an earlier context as generating greater opportunities for working directly with the person with dementia and following their agenda, although this is also likely to involve the information needs of family members as well. The experience of those people later in the journey is that the information is more frequently concerning behaviour which is perceived as challenging and availability of care services and frequently involves family members close to or in crisis;

> *"Because it's the progression another one's problems with their mobility and she didn't know how to get an OT assessment done, 'cause he's had a number of falls so I gave, told her to ring the Access Centre and explain what was happening... so that was for the OT. The other one was for benefits, because they hadn't been out to see him, and the other one was again trying to deal with challenging behaviour, another one's because she's deteriorated, she needs more care but there's problems with the funding"*

Signposting

Alongside the provision of information and advice, signposting is also viewed as a core component of the role of DA. The DA discussed two aspects to their role; populating the guide book and facilitating access to services.

Populating the guide book involved finding out about the resources available in their area and providing that information in an accessible format for people living with dementia and their families. This also involved getting to know the resources so that they knew who might benefit from it;

> *"Any resources in the community that we think are available, we want to check them out first, we don't want to send people to places that aren't appropriate. It's basically got a picture of the place, so people can identify it, then it has a bit of information about how much it costs, accessibility, parking, opening times, contact. We give them that information".*

Such activity continued throughout the period of the evaluation, with DA finding out about possible sources of meaningful activity and passing this information on to people who had expressed an interest in a particular form of support.

The DA discussed the signposting aspect of their role in some depth during the early stages of the development of their role. It was perceived that signposting was more than ensuring people have information about services;

> *"I think it is more than that because it is enabling people to access services. I see signposting as just giving out a phone number and that's it. Whereas we'd help somebody to phone up, to organise transport, speak to people, arrange for them to go for a taster session or something, it's not just signposting, it is more than that".*

However the DA highlighted that this process could be quite complex, for example when signposting someone who needed a greater level of support;

> *"How do we know that it is right for that person? Or do we put a line through that and say we've done our job, we've signposted and now it is up to someone else... but who? If they have got no family, then you've got the problem with dial-a-ride and are they going to remember today is the day that is this club"*

Unmet Need

Additionally, this involved challenges where services were not available to meet the needs identified by people living with dementia or their families. The difficulties of unmet need became more apparent as they became more familiar with their areas, and as they perceived it, the limited availability of resources to enable people to live well with dementia, particularly where they needed more support to access these activities;

> *"I had a gentleman, I know they did country walks nearby, I asked him 'do you think you would enjoy that?' he went 'hmmm, I might' and I said 'shall I ring and ask, we could look at going?', it said it was accompanied, if he could befriend another gentleman the same age, he could enjoy that; but I rang to say could he take the dogs which are like his baby, and it was 'no', and I asked about it being accompanied and it was 'well there are people at the front and there are people at the back and in the middle, to make sure nobody falls back, because it is quite a big group' but then when I mentioned who I was she said 'oh he'd have to be accompanied"*

or where there were concerns about risk;

> *"I don't want to signpost anyone to use a service unless really you know the risks involved with that person. In day care, I have had somebody asking me 'what is in the community, where can I refer them to in day care', and I am thinking 'I know he has got mobility issues, how far has his capacity gone?', if you signpost somebody to use a service, and that person wanders off? I would feel terrible, or if that person couldn't interact. I think in some ways it is difficult isolating the two"*

Concerns about unmet need and lack of available resources continued throughout the evaluation with the DA raising significant and repeated concerns about the impact this had on their ability to support the people accessing their service.

Networking

Networking is integral to many aspects of the DA role, particularly in promoting the role, in generating referrals and in finding out about services and opportunities for meaningful activity. Networking was discussed as an aspect of the role in the majority of the interviews with the DA. The ability to network was crucial early on in embedding their role into the areas they were working in, particularly for one of the DA who is working in an area with less resources and available activities;

> *"I am really having to really network myself...I am constantly having to introduce myself, setting up presentations and talks, it is an area that in some ways is quite isolated. I know they are in need"*

This aspect of the role appeared to be quite challenging, with one of the DA highlighting that although they were seeing the value of it, they had not imagined previously that they would have to do so much networking. However eventually, they were able to see the benefits of the networking;

> *"I feel like I am constantly having to justify myself and sell myself, and then you get referrals coming in and you think yes! At last, my hard work is paying off"*

Working with Different Populations

The DA recognised that a core aspect of their role is to recognise the diversity in the population and respond to people who may be harder to reach. These populations included people living with dementia who live alone, people from black and minority ethnic groups, people who have hearing impairments and younger people who are living with dementia. Particular challenges were noted in meeting the needs of these different groups including generating referrals and working through an interpreter;

> *"I went to the Asian Men's Group ... It went ok, there were probably only two people that spoke English and there was an interpreter there so we just... I spoke and then she interpreted, but she said how difficult it was. Because certain words couldn't be interpreted"*

And finding appropriate resources that are responsive to need;

> *"One of my other younger ladies who's quite young, uh, did come along to one of the groups in Worcester, um, but I, I don't think it's for her to be fair. You know, she's uh, she's only 47 and to come along with a lot of older people, and I think that particular day they had telecare in, and she gets very easily distracted and bored and wants to go, and she left, so I'm trying to find something more yeah for, for the younger people really".*

Who Do We Provide a Service To?

Although much of the literature, including the National Dementia Strategy (2009), stipulates provision of support from DA is for people living with dementia and their carers, in practice the DA within Worcestershire believed that the core focus was to provide a service to people living with dementia. The DA service commenced 7 months before the Early Intervention Dementia Service, which resulted in a higher number of referrals being received for people who were later in their journey of dementia. Therefore seeing the family members involved in care-giving rather than the person living with dementia was more common;

> *"I have had a lot of carers as well, but I think that is a given all over because we all knew that was how we'd begin, because people's dementia is already quite significant, even with diagnosis. So you're not working for the people living with dementia, you're working with the families really".*

However this was not without its conflicts for both of the DA and linked to concerns about unmet need for one of the DA in a location without an Admiral Nurse;

> *"There is nobody there to pick up their needs, I feel really that I will have to do it, but then I have [people] coming at me saying 'well, you're not supposed to be working with the carers solely', so it's difficult really"*

As a consequence, both DA had to think carefully about their role with family members involved in care giving, and also refer on as appropriate;

> *"You know when you go in to someone and you can see when you interact with the family ... or the carer you're able to see, you can see this person isn't coping well. We're not trained to take on anything like that, that is a case where I would look in me and think "This lady needs a lot more in depth work, probably with more counselling and a lot more understanding than we can ever give". Then you know that that person is ready and really would benefit from the help of the Admiral Nurse because she's an expert in her field, that's where it is".*

The DA did however work towards engaging with the person living with dementia as well in these later referrals. This often required that they negotiate access with families, and may not see the person living with dementia in the first few contacts.

With the commencement of the Early Intervention Dementia Service (EIDS), the referrals for people earlier in their journey of dementia occurred. The DA welcomed this as an opportunity to have direct contact with people living with dementia;

> *“I could talk more to the [person] who had dementia, they were his decisions they were making, he had capacity so all the information I was giving about power of attorney, you know it is going to be solely going to be his choice, where before it was more the carer’s decisions”*

And they expressed the view that this enabled them to be more person centred in their approach;

> *“So it is still about giving his wife a break, but in a way that he was happy with; he didn’t just want to be shipped off to a day centre, it is trying to stay person centred whilst meeting different people’s needs.”*

The contact with people living with dementia earlier in their journey was often facilitated through joint visits between a nurse from the service and the DA. During these visits the DA spent time with the person living with dementia while the nurse worked with the family member. However, who the DA were there to see continued to be an issue even where referrals were received for people earlier in their journey. This challenge appears to be related not only to later referrals, where the person with dementia is more advanced in their journey, but also related to the recognition that many of the contacts that they have are with both the person living with dementia and their family members involved in care-giving. This requires a considerable level of skill and sensitivity to support the needs of all of the people present as referred to earlier. Where relationships are collaborative, this did not seem to be complex;

> *“Couple I met ... they were a lovely couple, and he’s aware of his diagnosis, he said he’s finding it difficult to come to terms with his diagnosis, and he’s aware that he can’t put names to faces like he used to, he sort of can’t, “I can’t remember people’s names like I did” but he wasn’t aware of his change in personality that his wife was talking about. And she said “I never know whether I should be talking in front of him, but I don’t want to talk behind his back” you know, and I asked him how he felt about that and he said he feels alright. His concern is “She’s getting upset,” that’s his concern”*

However in some circumstances, their work can involve managing a situation where the needs of the person with dementia may be undermined or they are talked about as if they are not there;

> *"Loads of situations you come across are like that, when you're asking the person a question and their partner is answering for them. And the worst is – and this has happened two or three times now – is when it is all very negative stuff and the person is listening; I hate when that happens, but I don't know a best way, I have tried veering away and looking at that person and asking 'is that how you feel?' and you've still got the person there going 'and of course you can't take her out because she's wet once or twice' and I was mortified by what he said, and I saw his wife's face as though 'I did not!'"*

The DA frequently raised this as a challenge to their work with people living with dementia.

4.4 Getting Out There

As can be seen from the discussion concerning the different aspects of the role, the skills, knowledge and attributes required of a DA are significant. This section further addresses the skills, knowledge and attributes DA need in order to be effective in the core areas of the role identified above. Achieving an impact in the role of DA involved skills, knowledge, attributes and experience in regard to their direct contact with people living with dementia and their families, and in their ability to work with other professionals, services and organisations. The 6 key areas shown in Table 10 appeared to be important in enabling the DA to be effective in their working practice.

Table 10: *Getting Out There*

Past Experience and Prior Knowledge
Learning and Reflecting while Doing
Counselling Skills
Knowledge of Dementia
Knowing the Area
Resilience

Past Experience and Prior Knowledge

Past work experiences, training and education were identified as being significant in enabling the DA to deliver an effective service with people living with dementia;

> *"I have also had experience of working 'hands-on' with people living with dementia and their families and carers. My previous role gave me knowledge about providing personal care to people living with dementia, and interacting in a person-centred manner"*

And with their families;

> *"I think my years in [previous job] working with latter stages has been a massive benefit to me, I do fully understand carer's needs, I do understand the challenges, I know what's coming; so it's nice that I can be empathetic because I do feel for people when I meet them and I know how difficult it can be".*

This prior experience and learning was frequently referred to as essential in order that they could appropriately address the needs of people referred to the service. Additionally, this previous experience also assisted them in networking and building relationships with professionals and other services.

Learning and Reflecting while Doing

In addition to using past experience, reflection and learning while delivering a service was also necessary to be effective. In particular, it was identified that seeing more referrals helped to develop confidence and learn from what worked especially when feedback was given on the value of the service they had offered;

> *"I think the more people we see, the more confident we are in what kind of things we come up against in our role, it is experience, it helps, we are learning what services are out there, what people want, what kind of issues come up again and again, it is easier then to offer the support because you have heard it from somebody else and if they have fed back that it is really helpful, then you can use that information with somebody else".*

One of the DA indicated that they actively sought feedback on their input with people living with dementia and their families. The experience over time was also important in this context, with one of the advisers indicating that this had allowed them to develop a more personal service;

"So I have learnt now, instead of, I think when I first started I was very much going out with this checklist in my mind of, you know, I must talk about absolutely everything cause otherwise I don't feel like I'm doing the job properly. Whereas now I'm much more able to sort of pick and, and choose, and then, as I say, when I send a letter out, I'll sort of go over what we've discussed, but I also say, in the future if you wanted to talk about this, or you wanted information on that, then I'll do that, rather than just going and doing a spiel. It feels much more sort of personal now".

This quote highlights that the process of reflection allowed this Adviser to critically consider her practice, identify what worked and what didn't work and build her skills from this. This reflection therefore involved the need for self-awareness, and the ability to know when personal barriers are influencing the ability to work effectively. For example the DA highlighted their natural tendency to want to make it right for the people they were supporting;

"We will find that hard because we are the sort of people who will want to do too much. It's about being clear, because I know I would want to go and pick that person up and take them to day care, but I can't. It's about being clear from the start"

This was particularly the case because they had all worked in previous roles where they were involved in direct hands on care. The DA valued the opportunity to receive peer support in this context, and also in working together to create opportunities for reflection and shared learning.

Counselling Skills

Past training and education opportunities which involved counselling skills were also identified as crucial to the ability to work well with people living with dementia and their families. These skills enabled the DA to demonstrate flexibility and sensitivity to the needs of the person receiving the service, in order to hear their concerns and work with their concerns rather than impose solutions;

"I think the main thing is that people like us to listen to them. We have both had qualifications in counselling and skills... I think that is the main thing, just listening to somebody. It only sounds like a small thing, ... just [to] have somebody take that in and not try and fix it straight away but just listen to what they have to say"

Knowledge of Dementia

A detailed knowledge of dementia is also a core requirement to manage the many different questions and experiences that people living with dementia and their families have.

> *"I think the knowledge of, of different types of dementia itself, that's been useful, when I've had to sort of, when people have asked um, about, 'cause we do get, well I do get asked when I go out what, you know, what's the sort of prognosis in a way. And although I'm not sort of going with the medical side of it, you know, I'm able to sort of talk confidently about it"*

As has been identified previously, the DA felt that this knowledge had largely arisen from past work experiences and training. In addition, the DA identified that the induction training was an important aspect of enabling them to do this well, but that this needed to be tailored to their specific needs based upon their past experience;

> *"There was a lot of things, for me I think the biggest one probably [is] challenging behaviour. That when people approach you about that, they are at a stage where they're thinking "I can't cope any more" and if we, we knew more about the way people could deal with those challenges...I would've rather... spent a whole day learning about, ...Talk about coping mechanisms and reading what's going on between the lines, how will people deal with that?" ... They'd be good to learn at the very beginning because you, the main people reason approach us say with diagnosis, coping mechanisms and knowledge, are the things you need to get your training on at the very beginning"*

Knowing the Area

Gaining an in-depth knowledge of the area was identified as important;

> *"Knowing the area really helps ... because you're sort of much more aware of, of what's out there. So, so it's sort of linking, as I say it's linking everything together and sort of feeling that if you're signposting somebody you know why you're signposting them and what they're gonna get out of it, and how it, as I say, how it all fits in really".*

Indeed one of the DA's believed that without the time to get to know the area before receiving referrals, she would not have been as confident in her direct work with people who use the service.

Resilience

The resilience of the DA was a key attribute. Resilience involved the ability to find solutions to challenges, the development of confidence and determination to succeed. Finding solutions to the challenges of the role emerged early in the experience of implementing the role, in relation to achieving referrals and frequently involved persistence and determination in identifying the right people to talk with and explore possible working relationships;

> *"To know what avenues to go down, to know who it is to speak to, we've had ideas and email and thought while we've got this time let's go and spend some time at the hospital, speak to patient liaison because that is where families are going to go with problems. So [we] emailed the manager of all that and she's said she will get back to us, she's said 'let me know if you need anything from us', so we're trying to think of different avenues really"*

This also involved tenacity in being able to keep going back to the key people who might be able to offer referrals, even when the response hasn't initially been very positive;

> *"So what I decided to do is well it doesn't go on one person what do is I'll just put my foot in slowly, so I made arrangements and I did shadowing one-by-one and got to know people in the team that way. You know, there's always a way in. And it's more about showing them I think and coming to grasps with it"*

Developing confidence in their practice and their understanding of their role was also necessary early in the experience of the service. The DA recognised that their role was challenging to others and that they needed to be able to sell the benefits of the role confidently;

> *"Let's face it, in the beginning we didn't really know what, how you were going to do that because you weren't quite sure yourself how you fitted in, I wasn't. When I first went to meet the [practitioner] for the very first time I was like "Well a lot of this is grey areas" and you know, you're stepping on people's toes and not quite sure. But there is a clear difference. There is a clear difference, and there is a way of working in partnership, it's just it was difficult to say until I worked with her, that you could actually see where it would work".*

Developing confidence in their role came with receiving positive feedback from people who had received the service, and subsequently the DA were able to use these examples to illustrate their work when promoting their role and additionally to value their achievements.

4.5 Facilitators and Barriers to Working Successfully

A number of facilitators and barriers were evident in enabling the role to become embedded. Some of these have already been explored in other sections, including the attributes, skills and knowledge of the DA. However a number of other facilitators and barriers have become evident through the evaluation. These are shown in Table 11.

Table 11: *Facilitators and Barriers to Working Successfully*

Effective Management and Support of the DA
Partnership Working
Knowing the Boundaries of the Role
Being outside of the Statutory Agencies
Preparation of the Area
Unmet Need

Effective Management and Support of the DA

The experience of the DA throughout the implementation of the service has been highly challenging at times. These challenges have included:

- The preparedness of the area to receive the DA;
- The receptiveness of other services to the role;
- The length of time it took to receive referrals;
- The emotional experience of providing a service to people with complex and emotionally demanding needs.

The emotional journey that the DA experienced in carrying this role out is evident in the discussions of their role and the knowledge, skills and attributes they required in order to work effectively. A core attribute of the DA has been an emotional resilience and the capacity to use appropriate strategies to manage the impact upon them as individuals. While it is evident that they had many positive experiences and that they were able to use these productively to enhance their confidence in their work, it is also necessary to recognise the considerable challenges they faced. Personal resourcefulness was a key characteristic of the DA throughout the period of the evaluation, using skills such as reflection, reframing and exploration of alternative approaches. Nevertheless, the support provided to and needed by the DA is also particularly significant. The DA have highlighted the importance of having regular and ongoing management supervision;

"Well supervision like, we talk to [manager] ... The other week I did my own, I went out 'cause [DA] couldn't do visits on her own, so I've been going out with her. And doing mine, and the other week, think it was last week or the week before, I did my two visits on the Friday morning, and then I went with her and I did two for her, but I did say to [Manager] yesterday "I wouldn't do that again""

The DA went on to explain how important it was to be able to take these issues back to their manager and explore how to address them in the future. The DA had also found that the support they received from their manager needed to assist them to consider ways of managing challenges they faced. This included management support when visiting resources where they experienced resistance in order that they are able to create alternate opportunities for engagement with those resources.

The DA also found that in the early experience of the service, working together was of particular importance. The benefits of this included developing confidence in networking, where they felt able to communicate a clear message about the service, to provide each other with moral support and to ensure that they are able to present the service in a professional manner. They also recognised that it was quite intimidating to do this to large groups of professionals and that as a consequence they felt a sense of shared support in working together. This was particularly important for two of the DA involved in the demonstrator site, as they were pathfinders for the development of the role in Worcestershire, and needed as a consequence to develop a shared identity.

The opportunity to be involved in regular peer support was also considered to be very important;

"I've found peer support has been absolutely invaluable I have to say that it, it's, you know, just, you know, because when you start a new job you've got different ways of working, you don't want to sort of say the wrong thing... And it's that sort of, how do you address the emotional sort of peer support ... 'cause we did have an actual session in one of the meetings where we talked about how, you know, how to people relax, how do you switch off, how, how do you deal with the stresses, who do you talk to? You know, how do you use your peer support, and I thought that was really important, and really good"

The DA experienced challenging situations and found that peer support created opportunities to share these experiences and explore alternative ways of responding, as well as being able to express the emotions associated with the experience in a safe environment. It was also interesting to note that the experience of being involved in the evaluation and these interviews also appeared to provide a form of peer support, and it was acknowledged by one DA, that the recently appointed DA in the other areas did not have access to this opportunity or involvement in the action learning set. The DA indicated that they had found this to be beneficial to their development;

> *“I think probably, [DA] coming here and speaking to you about it, you offload, even though you’re doing this [evaluation]. But for the other DA, they don’t have anything like that at all”.*

The DA have also identified sources of support from within mental health services, in particular staff working within the Early Intervention Dementia Service and the Admiral Nursing Service. DA indicated that these professionals had provided support to consider individual clients they have been working with and more generally in terms of enabling the role to become embedded.

Finally, the DA also referred to the support and training received from the wider demonstrator site meetings, although at times this appeared to be a double-edged sword,

> *“The hard part was doing training in such big groups, the advisors were on the same training and different areas are working differently and that caused confusion. You thought ‘I know what my job is and I know what I have to do’ but then you got ‘We’re not doing it that way here’, it took me a while to think ‘take the training in but remember the remit you’re working to’”*

Partnership Working

A significant challenge for the DA early in their experience of developing the role was that the Early Intervention Dementia Service did not commence operation until 7 months after they came into post. This required that the DA’s developed alternative strategies for receiving referrals and necessitated the identification of key players who the DA could work alongside. Key players were identified in a wide range of services including Admiral Nursing, Consultant Psychiatrists, Community Mental Health Team Staff, Liaison Nurses, Social Workers, Town Hall Advisers and Carer Support Workers.

> *“With Admiral Nurse yeah, she’s been pretty good really, when she introduced me we explained what my role is and she said we will be crossing paths and working together, so that was a more positive day yesterday. She also gave me a list of everyone and what their job role was”*
> *“So I rang [carer support worker] back and I said “Do you work with” she said “We work with the family and what we’ll do is we’ll liaise with the ward we’ll raise the concerns the family’s got and we’ll contact the family.” ... And it was good to know in advance... you can contact her within that team if you need to”*

As indicated in the above quotes, key players were not only a possible source of referrals but also a way of finding others who the DA might liaise with and signpost to. Key players were able to convince others of the value of the role;

> *"I think I've been very lucky because I think having [consultant] based there was a really good thing, because he was so positive about it, it kind of rubbed off on everyone else. And he's very good at explaining things, so he could explain it to everybody before we even started"*

In one of the areas the service was located in, identifying key players was particularly difficult and resulted in a lengthy delay in the understanding of the role and thus the receipt of regular referrals. While this is not the only reason for the significant lead in time before the service became embedded, it is nevertheless the DA experience that the turning point for the receipt of regular referrals did not occur in this area until towards the end of the demonstrator pilot, sometime after the Early Intervention Dementia Service had been established.

However, with the establishment of the Early Intervention Dementia Service*,* the opportunities for partnership working were considerably strengthened;

> *"The nurses in the early intervention team all accept our role and accept us as being part of their team, so that's been really helpful".*

This has resulted in the development of strong working relationships, which have involved joint visits and collaborative working;

> *"And then we'll go in and then [EIDS Nurse] will ask how things are, whether they're on medication, and how that's suiting, and she'll talk about, you know, the times coming up. Maybe, sometimes they're not still ready for discharge, but she'll say she felt it was a good time to bring me in. And then she'll talk about her last visit, then she'll say is it ok if she talks, brings me in and they're usually fine with that, and she'll tell me what happened leading up to them going into the service really".*

Collaborative working with EIDS enabled the DA to see people earlier in their journey and additionally work specifically with the person with dementia, therefore fulfilling the role as they had envisioned it working earlier in their development. For one of the DA, being based with the Early Intervention Dementia Service was also identified as being particularly helpful in that the Adviser could see how things could progress. This collaborative working resulted in a significant boost to the confidence and sense of achievement the DA experienced as they felt that they had been given the opportunity to move forward in a different way because they had been referred people with MCI and early dementia.

Knowing the Boundaries of the Role

The DA found the early experience of developing their role challenging, in part because they felt that clarity concerning the nature of their role wasn't always present;

"The job description and specification has changes a few times already, so if it was set out from the beginning it would have helped us feel more confident initially"

However, they also acknowledged that the lack of clarity was also useful at times;

"On the other hand, its 'suck it and see'. That's the joy of it being a pilot".

They began to achieve greater clarity concerning the role through the beginning of the middle period of the pilot, around June 2010, and as a consequence, felt more confident concerning what they could do and what was not possible, including when it was appropriate to stretch the boundaries;

"I think that we know what our role is now, it helps a lot, clear specification and guidelines, that is good – I don't always stick to it, as I said before, we are only supposed to be working with the person with dementia, but we also work with carers, but we know what our role is, and It has helped me to feel more confident"

Developing this confidence resulted in the DA being able to sell their role more effectively by giving examples of the work they do to the services they liaised with, to generate referrals;

"We're able to give examples now, because we've had the experience, whereas initially it was just like reading off a piece of paper really".

This confidence in knowing the boundaries of their role has assisted them in developing their role with the Early Intervention Dementia Service, clarifying what they are able to do in their collaborative working with the team;

> *"One of the [team members] had referred to me and said um, you know, "I've told this chap that you'll escort him to a luncheon club." And I was like, "Well that's, that's, that's more support work," you know, that's. I will take, in order to get his confidence, and I will explain to him, you know, that we will go together ... once I'd met him the first time I thought "Yes he probably would go on his own, if he liked it.""*

Working within the Voluntary Sector

Being a non-statutory service was identified as an advantage in their contact with some of the people who have been referred to the service, or have self referred;

> *"The second couple I met, although he accepted information from me, and we sat and chatted. I said 'down the line if you needed to get a social worker or a CPN', he said 'we have always been private people, we have always been very me and her, we don't like outsiders' ... but for him, he felt that the CMHT would be an invasion, that's how it came across. He said 'we're coping right now , and we don't want anyone involved, I cannot see me reaching that stage, but I may reach that stage eventually"*

It appeared that the people referred to the service who expressed this view were concerned about the nature and type of input that involvement with statutory services might bring. However they did not appear to regard the DA in the same way and as a consequence were happy to have contact with them. As implied in the quote above, it is possible that the reasons for this include the level of perceived control that statutory services might have within their lives. However it was not always positive, being outside of statutory services meant that their views and opinions were not always respected by other professionals;

> *"And we also thought some people have been very positive about the service but other people have seen it as a bit of a threat I think. So you just have to be aware of that. You do come across all sorts really. You know, you may go and talk to people and it seems like a positive thing, but you get very little back from it really, there's a lot of tokenism out there. So, it's just a matter of keeping up. Also we've felt a lot that we've had to justify our roles and justify us being employed to do them as well".*

Preparation of the Area

The preparation of the area in order that the DA is accepted, their role is understood and the services are available for the Adviser to signpost people to was perceived to be crucial in lessening the time before referrals began to be received and in continuing to receive referrals throughout the pilot. The two areas where the DA were located were significantly different in this regard.

One of the DA had a very positive experience from early on in regard to the receptiveness to their role;

> *"They thought it was good because they said once somebody's been diagnosed there's not really much support for them after diagnosis, they tend to just get - unless they're later stages and they get a lot of involvement – if they're early stages and have had a diagnosis they tend to just get left really"*

However the other DA found that there was less understanding of their role and a resistance to their work;

> *"When I went to meet the [service] over at [area of work] it obviously bothered her, and why it bothered her I don't know, 'cause I'd already met with the family who she'd had dealings with ... And that was when I was asked to justify what my background was and what I'd been doing, in front of a whole group of people. You know, and I thought "Hmm, obviously an issue going on" but I don't even know what it was really".*

Preparation of the areas included that services needed to be available and greater preparation of staff that were going to be working alongside the DA. Additionally the involvement of key personnel from the area in the initial set-up of the service, and in promoting the role was thought to be helpful as was identified earlier, and where this wasn't happening it was felt to cause difficulties;

> *"I think, it's like I can't understand, when we went to the ... strategy meeting why there isn't anybody from [area of work] represented there, I'm not sure they understand the role and I don't know how much… if they don't feel like I can be any use, then how much do they understand the role? I thought they did before I arrived but they didn't, I don't think they do. They knew there was a DA but I'm not sure they grasp what it is"*

Finally, preparation of the area also included establishing where the DA were going to be based. As has previously been mentioned, one of the DA was based within the Early Intervention Dementia Service office and felt welcomed there from the beginning. This assisted her in establishing her role early in the development of the role and resulted in her receiving referrals right at the beginning of the development of the service.

Unmet Need

From as early as March 2010, the DA began to identify areas of unmet need. This was particularly evident in one of the areas where the DA felt there was a significant lack of awareness of dementia and as a consequence a significant lack of resources to meet need;

> *"What I have learned is that [area of work] is desperate for anything. When I met with the consultant, she said how desperate [area of work] is. The signposting is more difficult for me because there is nowhere".*
>
> *"The signposting side of it is difficult for me in [area] because I have had a lot of referrals come through [mental health service], and they have nowhere to send people who have finished the cognitive therapy, but I am in the same boat as them, they're frustrated because they've got nowhere, after 10 weeks they have to discharge them and they've got nowhere to send them, and I have the same problem"*

The types of unmet need highlighted by the DA spanned across the journey of dementia. Early in the experience of dementia, the Advisers highlighted the lack of opportunities for meaningful activity and occupation which was supported, to enable the person to live well with dementia;

> *"I've got another one who I, he's just come out of hospital who again is a younger man, and um, he's been signposted to me because his is activities, he is living in an older person's complex, but he's 65 years old. There are no facilities there. They have got him to go in to bowling now, which he's gone. But he enjoys cooking; I've tried to see if there was any cooking classes. If there was something like that for him but again it's the social activity we're looking for, for him"*

Additionally the DA highlighted the need for a befriending service, and indicated that this is not currently available, but is frequently something that would resolve some of the needs expressed by people using the DA service. On occasions the DA indicated that stigma and lack of understanding contributed to a lack of resources available to meet people's needs;

> *"I found the woman that ran the club, or whatever, I found that disheartening, the moment I mentioned the word... 'Oh you want to come along, well we don't have anyone like that'...well how could you know? And then after a while she said 'shall I have your number and if I come across anything I think is suitable?'"*
> *"When we mentioned about the dementia cafe hopefully starting ... she sort laughed and said 'who wants to go to a dementia cafe when it has got a big label across it?'"*

As the person with dementia developed a greater level of need, for example in needing support to be able to travel to and manage activities independently, the DA continued to identify a lack of provision, particularly for activities which were tailored to the person's interests;

"A lot of people middle stage, early into middle stage don't need a secure environment, they just need something within the community, but they may still need some support to access that, and someone just to keep their eye and make sure they're alright when they're there. And make it fun for them and help them build friendships and that".

"It's still the same thing. I had a lady rung me, I've spoke to her twice now. She works full time, she's got her own business and she's struggling. Mum's gone round to the neighbours a few times, she lives on her own mum does, she's gone round to the neighbours a few times, her daughter's concerned. Mum's trying to go out, she's worried about mum's safety, and she said "I think it's 'cause she's bored, but what can I do? I work full time, I don't know what to do" Um, she's gonna try and bring mum to the cafe. But it's once a month".

And although there are more services available for people who are much later in their journey and need a more secure framework of support to manage risk and offer appropriate activity, the waiting list for accessing such services is a source of difficulty, particularly when some of the referrals received by the DA have been for families who are close to crisis and need some support as soon as possible;

"If they need more, if they're looking at respite, or day care, or needs in that way, then we know the straightforward thing is they need to contact the Access Centre and get a, get a carer's assessment done. What concerns me about that at the moment is the amount of people waiting for carer's assessment because they're overflowing at the moment. Because you're going out to people who've had a diagnosis and are, kind of on the verge of already struggling, but the partners are not well either"

Of particular concern to the DA is the need for the services to be tailored to individual needs, for example for a younger person to be placed in a centre with people who are much older than him may be completely inappropriate;

"I had somebody yesterday, she was quite distressed, her husband is only 68, she said he doesn't like sitting in a room with older adults, there is nothing available for him, he's too old for Al's way because his diagnosis was only about six months ago, and he is too young for all the nursing homes, so that is a bit of an issue".

Finally, it is important to recognise the significant emotional impact that not being able to provide people with appropriate services had on the DA. While they demonstrated considerable levels of resilience during the implementation of the service, frustration in relation to the lack of services was a continuing theme throughout;

> *“So you feel a bit frustrated really. He was telling me how he went into [city] the other week because they’d had a row, off he’d gone on a bus, he told me where he went, he said he was born there in the [city], and then caught the bus back [home]; his wife was quite concerned but ... she said she had tried a day care but he only went twice and said ‘why are you doing this to me, I don’t belong there, I don’t want to be there’ so she had to stop him going; basically, he’d love a game of golf, that is all he wants, he took me to show him his golf clubs and he would just love a game of golf”.*

The continued lack of appropriate services to signpost people on to has been a major barrier to the success of their work, influencing their capacity to improve the quality and enjoyment of life for people living with dementia and their family members.

4.6 Summary

This chapter has explored the experience of becoming and being a DA for the 3 Dementia Advisers who have been part of the demonstrator site. 3 overarching themes were explored:

- The Role of the Dementia Adviser
- Getting Out There
- Facilitators and Barriers to Working Successfully

The Role of the Dementia Adviser

The DA highlighted the importance of working alongside the person living with dementia and their family members throughout the journey of dementia. This involved establishing trust and ongoing contact, which was most effectively managed through joint visits with EIDS. It additionally was most effective in achieving ongoing contact when it involved initial face to face meetings and maintaining contact with people who had previously used the service at regular intervals. Nevertheless, providing the service in this way can be emotionally challenging, and as a consequence support and supervision is a necessary facilitator to the work of DA.

In meeting the needs of people who use the service, the DA described a number of aspects to their work. Initially this involves assessment, and requires the DA to have a breadth and depth of knowledge concerning dementia, resources and the experience of living with dementia. Additionally, assessment involved interpersonal skills including the ability to listen and manage competing needs experienced by people living with dementia and their families.

Following assessment, the types of intervention provided by DA include information and advice on a range of topics such as:

- health and wellbeing
- dementia
- benefits and entitlement
- planning for the future
- working and driving

Thus demonstrating the breadth of knowledge required of those in the role. The DA highlighted the sensitivity and interpersonal skills needed to deliver this information, involving consideration of what level of information is required, how it should be delivered and how much is appropriate to give at any point in time. The nature of the information required was also dependent upon where people are in their journey of dementia and whether they were a person living with dementia or a family member.

A further aspect of the role was that of signposting. DA identified that they signpost people to relevant services, but that this signposting is considerably more than giving people information and contact details. In this role, signposting includes finding the right forms of activity, occupation and services and as appropriate, assisting the person to access these resources. Such work is dependent upon the networking carried out by the DA and the effectiveness of the guidebook as well as the local knowledge of the DA. This aspect of the role has raised significant concerns about unmet need within the areas the DA work, particularly for meaningful activity and occupation for people who require support and supervision to live well with dementia.

A core aspect of the work has involved promoting the role and networking. DA have emphasised the considerable time that has been required to inform others about the role in order to facilitate understanding and ultimately referrals. This work has continued throughout the pilot phase and has involved:

- Identifying key players within different services
- Selling the role
- Providing a justification for their role
- Maintaining their contact with these services in order that referrals are made

Additionally this aspect of their work has involved raising awareness concerning dementia with individuals and organisations.

A final aspect of this theme has been a consideration of who the service is for. Two main issues emerged in this context, providing a service to different populations and considering whether the service is solely for people living with dementia or if this should include family members. Providing a service to different populations has involved recognising that there are groups who may be experiencing specific needs, who require a service from the DA, including people living with dementia who live alone, people from black and minority ethnic communities and younger people living with dementia. Again, unmet needs have arisen in beginning to address the support needs the DA have identified when receiving such referrals.

The different starting points for DA and EIDS resulted in the need to gain referrals from other sources, thus DA were receiving referrals for people living with dementia much later in their journey. A consequence of this was that their work involved and included family members more frequently than the person with dementia. Family members have therefore been recipients of the service both as referrals in their own right and in the context of their relationship with the person with dementia. Although this imbalance has increasingly been addressed through their work with EIDS, it has nevertheless raised some important concerns for the DA in regard to who the service is for, particularly as even in the early experience of dementia, the DA often meet with both the person and their family members. Additionally, the DA have experienced particular challenges in managing the needs of both parties where conflicting needs have occurred.

Getting Out There

In considering the skills required of DA, 6 areas emerged from analysis:

- Past Experience and Prior Knowledge
- Learning and Reflecting while doing
- Counselling Skills
- Knowledge of Dementia
- Knowledge of the area
- Resilience

Some of these issues were highlighted in the section concerning the role of DA, but warranted further exploration as a result of the experiences of the DA. Having past experience and knowledge was considered an essential characteristic. Prior knowledge and experience enabled DA to work effectively with people referred to the service, and respond appropriately to the needs that emerged from assessment. In particular, this assisted the DA to respond empathically and sensitively to the concerns being expressed. The capacity to reflect and learn from experience was also a necessary skill, enabling the DA to develop in their role. DA emphasised the importance of counselling skills identifying that the ability to empathise and actively listen underpinned their interventions with people living with dementia and their families. In particular it was evident that such skills enabled the DA to sensitively respond to complex situations such as advanced planning and questions about dementia.

DA also require a detailed knowledge of dementia. They identified range of questions and issues that are raised during their interventions, which require that they are well prepared and have appropriate levels of preparation for the role and ongoing education while delivering the service. Knowledge of the area was also identified as important. In particular, that getting to know the area before seeing referrals assisted in being confident that a service could be offered.

Finally a core characteristic of the DA was that of resilience. The DA described many challenging experiences during the demonstrator pilot, including:

- Finding solutions to challenges, particularly where receptiveness to the role was poor;
- The development of confidence in their practice and their understanding of their role in the context of a lack of clarity about how it would work in practice;
- Determination to succeed in their role despite the long time it took to become established;
- Delivering a service in the context of poor awareness and low levels of resources to signpost people to;
- The emotional journey involved in delivering the service.

Resilience was demonstrated as a key characteristic of the DA throughout the period of the evaluation, using skills such as reflection, reframing and exploration of alternative approaches when experiencing these challenges.

Facilitators and Barriers to Working Successfully

6 themes emerged from analysis:

- Effective management and support of the DA
- Partnership Working
- Knowing the Boundaries of the role
- Being Outside of Statutory Agencies
- Preparation of the Area
- Unmet need

The DA experience many challenges during the period of the demonstrator site, these have included:

- The preparedness of the area to receive the DA;
- The receptiveness of other services to the role;
- The length of time it took to receive referrals;
- The emotional experience of providing a service to people with complex and emotionally demanding needs.

While resilience was a key characteristic of the DA during the pilot, a further facilitator was the management and support provided. The DA highlighted the importance of having regular and ongoing management supervision, working together with the other DA to develop confidence and identity in their role, and peer support to enable them to cope with the challenges experienced. DA also identified sources of support from within mental health services, in particular staff working within the Early Intervention Dementia Service and the Admiral Nursing Service. DA indicated that these professionals had provided support to consider individual clients they have been working with and more generally in terms of enabling the role to become embedded.

Partnership working was an effective strategy in enabling the role to become embedded. Key players were identified in a wide range of services included Admiral Nursing, Consultant Psychiatrists, Community Mental Health Team Staff, Liaison Nurses, Social Workers, Town Hall Advisers and Carer Support Workers, as well as the Early Intervention Dementia Service. Key players were not only a possible source of referrals but also a way of finding others who the DA might liaise with and signpost to. Key players were also important in convincing others of the value of the role. Collaborative working with EIDS enabled the DA to see people earlier in their journey and additionally work specifically with the person with dementia, therefore fulfilling the role as they had envisioned it working earlier in their development. Furthermore, being based with the Early Intervention Dementia Service was also identified as being particularly helpful.

Developing an understanding of the role over time was a facilitator to effective practice. Developing clarity concerning the boundaries of the role resulted in the DA being able to sell their role more effectively by giving examples of the nature of their work to the services they liaised with, which resulted in referrals as people developed a greater understanding of how they could work together. This also enabled the DA to clarify what they are able to do in their collaborative working with others.

Being a non-statutory service was identified as an advantage in the DA contact with some of the people who have been referred to the service, or have self referred. It is possible that the reasons for this include the level of perceived control that statutory services might have within their lives. However being located outside of statutory services was not always positive, DA found that their views and opinions were not always respected by other professionals within statutory agencies.

The preparation of the area in order that the DA is accepted, their role is understood and the services are available for the adviser to signpost people to was perceived to be crucial in lessening the time before referrals began to be received and in continuing to receive referrals throughout the pilot. The two areas where the DA were located were significantly different in this regard. Preparation of the areas included that services needed to be available and greater preparation of staff that were going to be working alongside the DA. Additionally the involvement of key personnel from the area in the initial set-up of the service, and in promoting the role was thought to be helpful.

Finally, the DA experienced considerable challenges in regard to unmet need, particularly in one of the areas served by the demonstrator pilot. The types of unmet need highlighted by the DA spanned across the journey of dementia. Early in the experience of dementia, the Advisers highlighted the lack of opportunities for meaningful activity and occupation which was supported, to enable the person to live well with dementia. This was particularly the case if the person living with dementia required ongoing support to access these activities. Additionally, on occasions the DA indicated that stigma and lack of understanding contributed to a lack of resources available. They additionally highlighted that there was a need for a befriending service. Later in the journey, although some resources were available, the DA found that the waiting lists were problematic, particularly in the context of working with families who were already struggling to cope and were near crisis. Concerns about unmet need were also raised in the context of a lack of services tailored to individual needs for younger people living with dementia and other disadvantaged groups. The DA experienced the lack of appropriate services as a major barrier to the success of their role.

Chapter 5: Stakeholders Perspectives on the DA Role

5.1 Evaluation Methods

Semi-structured interviews were completed with people who were in a position to influence the work of the DA, either as referrers to them; as managers responsible for their work; as commissioners or as agencies who would be working alongside the DA. These interviews were carried out at two time points, in April/ May 2010 and then again in February/ March 2011. Initial interviews were limited to those who were regularly in contact with the DA or influencing the work as it was taking some time for them to become established. The second time point involved a broader range of participants from the group identified above. These participants are identified below in Tables 12 and 13.

5.1.1 First Time point April/ May 2010

Table 12: *Stakeholder Participants - Baseline Interviews*

Participant	Role
SH 1	Alzheimer's Society
SH 2	EIDS Worcestershire
SH3	Commissioning Role

5.1.2 Follow up February/ March 2011

Table 13: *Stakeholder Participants - Follow Up Interviews*

Participant	Role
SH 1	Commissioner
SH2	Commissioner
SH3	EIDS Worker
SH4	EIDS Worker
SH5	EIDS Worker
SH5	EIDS Worker
SH6	CMHT
SH7	CMHT
SH8	Alzheimer's Society

In addition to these stakeholders, it was also intended that the views of organisations in receipt of referrals from the DA should be sought. In practice, this proved to be impossible to achieve within the time frame of the pilot. This was because it took a considerable amount of time for the service to become embedded in both areas. Furthermore, considering the impact of the signposting activities of the DA, it can be seen in Chapter 6 *(page 116)* that the main areas of signposting (with the exception of the Alzheimer's Cafe's) occurred to organisations such as the access centre for social services, thus it would not be possible to gain their perspectives on the impact of the DA service. Information concerning the DA's views on their signposting activity is included in Chapter 4 and data concerning signposting activities is included in Chapter 6.

5.2 Results

Stakeholders were asked to consider 9 questions exploring the following areas:

- Can you tell me what you believe to be the purpose of the Dementia Advisor Role?
- How do you believe this role fits within existing service provision for people with dementia?
- What in your opinion will be the measures of success of the role?
- What do you believe are the barriers to implementation of the role?
- What areas of competence do believe the dementia advisors need to possess in order to be effective in their role?
- What personal qualities do you believe the dementia advisors need to possess to be effective in their role?
- Since the dementia advisors have been in post, what in your view have been the challenges and learning points in the implementation of their role?
- Is there anything that you believe needs to be resolved in order for the Dementia Advisor Service to move forward?
- If you were setting up the service from this point, what would you have done differently?

Data obtained from the interviews was transcribed and anonymised. Analysis was carried out using line by line thematic analysis (Ryan & Bernard, 2003; Braun & Clarke, 2006). Transcripts were coded to develop major themes and sub themes, employing both inductive analysis (derived from the experience of the participants) and deductive analysis (derived from literature and the experience of the researcher). Analysis considered the experience over time as well as the common themes arising from all of the interviews. Results from the first time point and second time point are presented together, with differences highlighted where these exist.

5.3 Role of DA

The role of DA was defined as primarily for people living with dementia, but engagement of those supporting the person was also felt to be necessary. However by the second time point interviews, it seemed that stakeholders were more convinced that they should be there for carers/ families as well as person with dementia

"They are a point of contact throughout the person's life, primarily for the person with dementia but obviously they do also deal with family members, carers"
"A point of contact for people with dementia and their carers, their families"

As indicated in the previous quote, the role is also seen as providing a single point of contact throughout the journey of dementia

"To offer people that've just been diagnosed with information regarding the diagnosis, and ongoing support throughout their journey, it's right at the beginning and they will stay involved for life"

The facets of the role that were identified included:

- Enabling people to access services

  "A useful resource in terms of signposting... onto services outside"

- Provide information plans

  "Timely and appropriate information and guidance"

- Future Planning

  "Helping people to plan for the future"
  "To navigate people through the dementia care pathway"

Signposting and information included the range of experiences that made life meaningful for an individual, so was not limited to information about dementia and services related specifically to dementia itself. This therefore included for example, information concerning finance, social life and keeping healthy. Information giving was also viewed to involve helping family members to understand the experience of dementia;

"Helping the husband to understand the symptoms that his wife is exhibiting"

Stakeholders indicated that in order to signpost effectively, the DA needed to have extensive knowledge of and good links with services in their area. This was viewed as a significant part of their role, involving;

"[Going] out and find where the information is and where the services are"

Some stakeholders identified that the work of the Dementia Adviser should focus upon providing practical support to people living with dementia and their families rather than emotional support, and that the role should not be about providing intensive support.

Some stakeholders saw the role as being able to positively influence the future through the potential to remove/ reduce crisis points;

> *"Rather than waiting for there to be a crisis, and them come referral for some emergency response, people can seek out a dementia adviser, start to ask for the right type of information and support, before things are getting too desperate"*

Finally, stakeholders highlighted the broader role of the DA in raising awareness of the dementia;

> *"They play a big part in the awareness building"*

5.4 How the role fits within existing service provision

Stakeholders identified that the role is to work outside of statutory organisations, but alongside them. Some stakeholders referred to their role as working alongside both statutory and third sector agencies including Age Concern, and indicated that being placed outside of statutory agencies allowed for them to be contacted directly;

> *"It's very well placed outside of specialist services for people to contact directly"*

The majority of participants thought that the role should be closely located within the Early Intervention Dementia Service (EIDS);

> *"Work very closely with the Early Intervention [Dementia] Service, to actually identify those people who've just had a diagnosis"*

Responses at time point two, when EIDS had been operating for 9 months, highlighted the value of this, indicating that DA were able to take referrals on once people had finished with EIDS;

> *"We've got a service for identifying and clarifying that somebody has dementia, and then a service for being helpful in that, from then on"*

Despite expressing the view that DA should be located alongside EIDS, there existed some confusion concerning when referrals should be made to DA, specifically whether this was pre-diagnosis or following diagnosis;

> *"At what point we should be referring to them, because we haven't really been until a diagnosis has been made"*

However some felt that the role was duplicating existing work if located within Secondary mental health services, and argued that they should be located within Primary Care;

> *"In Secondary care I think it duplicates"*
> *"I'm sure in Primary care; certainly before people get referred to [secondary mental health services] it is vitally important"*

5.5 How will we measure the success of the role?

The most common response to this question was that it was believed that the evaluation was too early to see the benefits of the role;

> *"Probably won't see... what impact the [DA] will be having until five, ten years down the line"*

However, stakeholders identified particular ways in which they thought the effectiveness should be assessed. These included:

- Data concerning numbers of contacts/ referrals, who and when people access the service;

  > *"The numbers of referrals, the numbers of contacts, the sort of demographic breakdown of who those referrals have been... just covering all the stuff around equality and diversity"*

- Interviews with people using the service, their families and data concerning quality of life and benefits experienced;

  > *"If the people use [the service] tell us that they've benefitted from it then that would be the main measure"*
  >
  > *"The ideal outcome is that people's lives are better"*

- Both short and long term outcomes were important, including impact upon crisis;

  > *"Dementia related emergencies and crisis dropping"*

But it was felt that outcomes such as delayed admission would be difficult to measure in the short term. Indeed it was argued by some that while reduction in crisis might be a by product of the service, it is not necessarily something the service can influence directly.

Further measures of success included the effectiveness of the signposting activities, and that people were more informed about the services available to them. However it was also recognised that this relied on there being services for the DA to refer people to;

> *"The DA role hinges on the fact that... as a signpost they have something to signpost to"*

5.6 Barriers to implementing the role

Some stakeholders believed that there had not been a good understanding of the role, or openness to the role in some areas and by some professionals;

> *"We've got some [professionals] within the county who are really keen on [the adviser role], pleased that it's there... other team members who feel quite threatened by that role"*

It was believed that this had impacted upon numbers of referrals and people knowing it was there. Concern was expressed about the negative attitudes that existed, which were evident in the way that DA were asked to justify their role and their qualifications;

> *"They've been challenged on a personal level by people who want to know well what's their training, what's their background, what qualifications have they got, I mean you don't get that the other way round so, I think that's been quite difficult for them"*

A further barrier was that of lack of referrals. Referrals at time point one had been largely for people later in their journey and for families involved in care giving. Many families were at difficult and often complex points in their journey, which made it difficult to address their needs when they hadn't necessarily had a good experience to that point. At time point two, the slow referral rate was still an expressed concern;

> *"some concern has been raised about the rate of referrals"*

This referral rate may also reflect a lack of clarity concerning how to use the DA.

The third barrier highlighted concerned the capacity of the current services to meet the needs of people signposted on and the availability of services that would effectively meet need.

> *"Where I have anxieties, it's about a signpost that points to nothing very much"*
> *"In some areas, services don't exist, there isn't really anything in their local area that they can signpost them on to"*
> *"It's been frustrating for people to sort of go out and offer to signpost people and then not really have anywhere to signpost them on to"*

This barrier was perceived to represent a major limitation to the success of the role, and is likely to impact upon the DA ability to influence the quality and enjoyment of life for people using the service.

Stigma and labelling was also perceived to be a barrier to effective working, with some believing that the use of the word dementia was a problem for some people, particularly if the referral was made prior to being given a diagnosis. It was suggested that following diagnosis some were reluctant to engage with the DA, perhaps because of the stigma;

> *"They don't want somebody from the Alzheimer's Society called a dementia adviser coming to see them because of the stigma around that"*

Although not all of the stakeholders believed that the label had a significant impact;

> *"We haven't had that... sense that the name, the stigma attached is acting as a barrier"*

5.7 Areas of Skills required of a DA

Stakeholders were asked to comment upon the areas of skill the DA needed in order to be effective in their role. These were identified under 4 main headings:

1. Interpersonal and Communication Skills

   > *"I think communication is gonna be the biggest competence they need"*
   >
   > *"Be very clear; be able to get that message across really"*

   These communication skills were further described in terms of:

   a) Good communication skills listening as opposed to controlling/ listening
   b) Empathy
   c) Presentation skills
   d) Enabling the person with dementia to make their own decisions
   e) Needing to be able to communicate with a wide range of people at different levels
   f) Needing to be able to communicate dementia to the wider public

2. The ability to work well with others including people living with dementia and their families;

"Understand how other agencies work"
"Network with other professionals, talk at team meetings"
"Dealing with clients...professionals"

This included the ability to:

   a) work well with others at all levels
   b) be assertive and able to upwardly manage (in terms of working with people such as GP's and other senior professionals)
   c) Achieve credibility with services they work with
   d) Know when to ask for help and support
   e) Establish their role within EIDS and with other agencies
   f) Be flexible in their work with others
   g) Knowledge
   h) DA were identified as needing a sound knowledge of dementia that was not limited to the diagnosis itself

"Huge knowledge base really about dementia itself"
"The impact of having a diagnosis of dementia on the person and the family"
"It's pathogenesis, its development, the pathway of dementia"
"Advising people about practical management of symptoms"

3. Additionally it was felt to be particularly important that DA had knowledge of information and services available within their local area;

"Strong local knowledge base"
"Knowing what is available within a particular locality"
"Good knowledge of the services available within their local area"

4. Experience of Working with People with Dementia
   It was not felt by some that a qualification was required to be a DA, however prior experience of working with people with dementia, and the ability to use that experience was considered to be an important skill;

"It's everything to have that experience... the ones that've got the experience can give a lot more advice and support"
"[They can] draw on situations and events [they] have experienced"

5.8 The Personal Qualities of a DA

The personal qualities identified mapped closely with the skills that were believed to be necessary to work as a DA, including:

Personal Attributes

Responses in this section emphasise the personal attributes of DA, recognising that they are required to 'walk alongside' people in their journey;

> *"DA's need to take that journey with them, so relationships are very key with individuals"*
> *"Putting yourself in other people's shoes"*

and that this requires qualities such as:

- humanity and care for others
- diplomacy and tact
- value base
- personal character, committed, conscientious, feels strongly about improving things

Resilience and Self Management

At the first and second time points, stakeholders recognised the significant challenges that the DA had faced and thus, the capacity for resilience and self management were identified as particular requirements;

> *"Have confidence because they will get people asking them to justify whey they think they can do the job that they're doing"*
> *"Strong and strong willed, because they'll come up against challenges, they'll come up against barriers"*

This was further described in terms of being able to:

- Cope with uncertainty, be flexible and willing to adjust practice;
- Be persistent, patient and objective;
- Organise themselves, particularly in the face of competing demands upon their time and large amounts of work;
- Reflect upon their practice.

The ability to work with others was also seen as a core quality. In the context of the resistance to their work that had been experienced throughout the project, some stakeholders identified that;

> *"They need to be able to present their opinion quite well and not be aggressive, not be defensive, but equally not be passive either"*

Further aspects of this quality included:

- Conflict Resolution
- A sense of humour
- Being a communicator
- Adaptability and able to work with different people
- Openness
- Friendliness
- Enabling

5.9 Learning Points and Challenges

Stakeholders were asked to consider what learning points and challenges were associated with the role.

At time point one, one of the challenges associated with the DA service was that it was primarily designed to focus on the person living with dementia, but in practice the majority of referrals had been for family members in care giving roles, with the person with dementia being later in their journey;

> *"We've had a surprisingly large number of relative, carers who have come to us first"*

This highlighted a difference between the theory of how the role would work and the practice of delivering it in the context of a gap between the DA role starting and EIDS commencing operation.

Poor awareness and understanding of the role was also believed to be an important learning point;

> *"One of the challenges which has more to do with the people who would work with them... is as a new piece of service within our service mechanism many people have taken a long time to understand their roles"*

It was believed that this would have been addressed by more groundwork being carried out before starting the role and possibly by ensuring that the EIDS was in place at the same time. Additionally, it was felt that this was hampered by the location of the DA. Although one was based with EIDS, the other was not located there, or with other services. Their lesser presence in these areas was believed to limit opportunities for networking and developing a greater understanding of the role.

5.10 What needs to be resolved to move the service forward?

3 issues were identified by stakeholders:

1. Funding

> *"I don't wholly know about funding and whether or not that's going to be available for the long term"*

While the service has been extended across the county, the uncertainty about funding for the longer term was believed to be an area that needed resolving, particularly because it was perceived as difficult to sell a service as being there for the whole journey when uncertainty exists.

2. How to make use of the DA

> *"I think we may as well establish a principle for example that anybody with a newly-given diagnosis of dementia should be at least made aware of Dementia Advisers and offered the opportunity to meet them"*

Stakeholders expressed the view that more focus on how to integrate the DA into the work of EIDS should occur, making them an integral part of the care pathway.

3. Achieving clarity over their role

> *"Be clear about where they're trying to prioritise their work"*

Stakeholders identified the need to further develop professionals understanding of their role, including raising awareness of them within specialist mental health services as well as within Primary Care.

5.11 What could have been done differently?

Finally, the stakeholders were asked to consider what could have been done differently. Participants identified the following learning points:

1. Strengthening the governance arrangements
2. Greater clarity on how to make the best use of the DA, embedding them in as a standard part of the pathway
3. Achieving clarity over the role of the DA and how to access them
4. Raising awareness of them, more publicity/ awareness of the DA role in groups/ services and with wider public
5. Basing all of the Dementia Advisers within the EIDS
6. Doing joint visits with the Early Intervention Dementia Service to introduce the DA

7. Aligning the service more clearly with primary care
8. Have the EIDS in place first
9. Having all the DA in post at once
10. Being accessible to the General Public, open referral system
11. Greater publicity at the outset

In order to address some of these issues, stakeholders suggested that the service needed to increase the level of marketing, including working alongside Primary Care. It was suggested that in the future, localities needed to have appropriate levels of groundwork in regard to awareness raising before the DA role was implemented, along with greater publicity for the service and for dementia more generally.

Finally it is important to emphasise that positive feedback was given concerning the DA and their work;

The Role:
"Reassuring for people to know that support will continue after that in the form of the dementia adviser"
The People:
"DA has worked really well with the patients I have referred to her... she's liked, she's popular... she's liked by the patients that she sees, she's very approachable and very helpful and knowledgeable"

5.12 Summary

The role of DA was defined as primarily for people living with dementia, but engagement of family members and carers was also viewed as appropriate. Stakeholders perceived the role of the DA to include:

- Enabling people to access services
- Provide information plans
- Future Planning

Signposting and information included the range of experiences that made life meaningful for an individual. The DA were believed to require extensive knowledge of and good links with services in their area. Stakeholders also indicated that the DA provides practical support to people living with dementia and their families. Some stakeholders believed that the DA could positively influence the future through the potential to remove/ reduce crisis points, although this was not perceived to be a direct outcome of the service by others. Finally, stakeholders believed that the DA also raised awareness of dementia more broadly within the community.

DA were thought to be effectively located outside of statutory organisations but should work alongside them. Many stakeholders expressed the view that the role should be closely located with EIDS although some believed that the service would be best located in primary care.

In regard to measures of success of the role, some stakeholders felt that the evaluation was too early to see the benefits of the role. However it was felt that evaluation should address:

- Data concerning numbers of contacts/ referrals, who and when people access the service;
- Interviews with people using the service, their families and data concerning quality of life and benefits experienced;
- Both short and long term outcomes were important, including impact upon crisis.

Barriers to the success of the role were explored. These included:

- A poor understanding of the role and lack of openness to the role;
- A lack of referrals before the EIDS began making referrals to the DA;
- The capacity of the current services to meet the needs of people signposted on and the availability of services that would effectively meet need;
- Stigma and labelling was also perceived to be a barrier.

Stakeholders believed that the skills of the DA should include:

- Interpersonal and communication skills;
- The ability to work well with others including people living with dementia and their families;
- A sound knowledge of dementia that was not limited to the diagnosis itself;
- Experience of working with People with Dementia.

Additionally, the personal attributes identified by stakeholders included:

- ‘walking alongside’ people in their journey
- Resilience and self management
- The ability to work with others

Learning points for the development of the role included that the service responds to the needs of family members as well as people living with dementia and that further work is needed to establish and embed the role within services. Stakeholders considered what areas needed to be addressed to enable the service to move forward. Responses included achieving certainty concerning funding, greater integration of the DA into the work of EIDS and in primary care. Stakeholders also emphasised the need for post holders to have significant background experience of working with people living with dementia and their families. Finally it was thought that more awareness raising with professionals to develop understanding of their role was needed within specialist mental health services, health and social care and primary care. Stakeholders additionally identified what could have been done differently. Many of the issues raised were identified earlier in barriers and learning points. Further issues identified included:

- Strengthening the governance arrangements
- Basing all of the Dementia Advisers within the EIDS
- Doing joint visits with the Early Intervention Dementia Service to introduce the DA

Finally, stakeholders emphasised the value of the role, including that people living with dementia and their families had identified that they appreciated the support and interventions the DA had provided.

Chapter 6: Who used the DA and what were the interventions?

6.1 Evaluation Methods

All of the data presented in this section of the report has been taken from the Alzheimer's Society database used by the DA Service. It aims to show what the DA role involves, and how that role has developed during its initial period of operation. Wyre Forest, Redditch and Bromsgrove have a total population 98,100, 78,700 and 93,400 respectively (ONS Mid Year Estimates, 2010). The estimated prevalence of Dementia in Wyre Forest, Redditch, and Bromsgrove are 1,373, 810 and 1319 respectively (Worcestershire Dementia Strategy, 2011). Due to the differences in total population and prevalence of dementia, direct comparisons of the two areas covered by the DA Service need to be viewed with this in mind.

6.2 Results

This results section considers the referrals made to the DA Service from a number of different perspectives.

6.3 Number of referrals by area

This section considers the number of referrals made to the DA in Wyre Forest and Redditch & Bromsgrove areas to see how well the DA Service has been taken up.

It should be noted that the DA for Wyre Forest went on maternity leave at the beginning of November 2010 and although temporary cover was in place, a permanent replacement was not in post until late December 2010, did not start taking referrals until January 2011 and there has been a period of absence due to ill health, causing a further gap in provision.

A total of 329 referrals were received by the DA during the demonstrator pilot, 190 for Wyre Forest and 139 for Redditch and Bromsgrove. A breakdown of the referrals each month can be seen in Figure 1, and shows the break due to maternity leave. It can be seen that although referrals began to be received right from the start of the DA Service, the number of referrals for people living with dementia was fairly low throughout the whole period, reflecting the long process involved in embedding the service within the localities. The low number of referrals in June 2010 reflected a difficulty with ensuring that referrals were sent through to the DA from the referring agent.

It can be seen that referrals for family members/ supporters involved in caring outnumber the referrals for people living with dementia, although they are not intended to be the target clients.

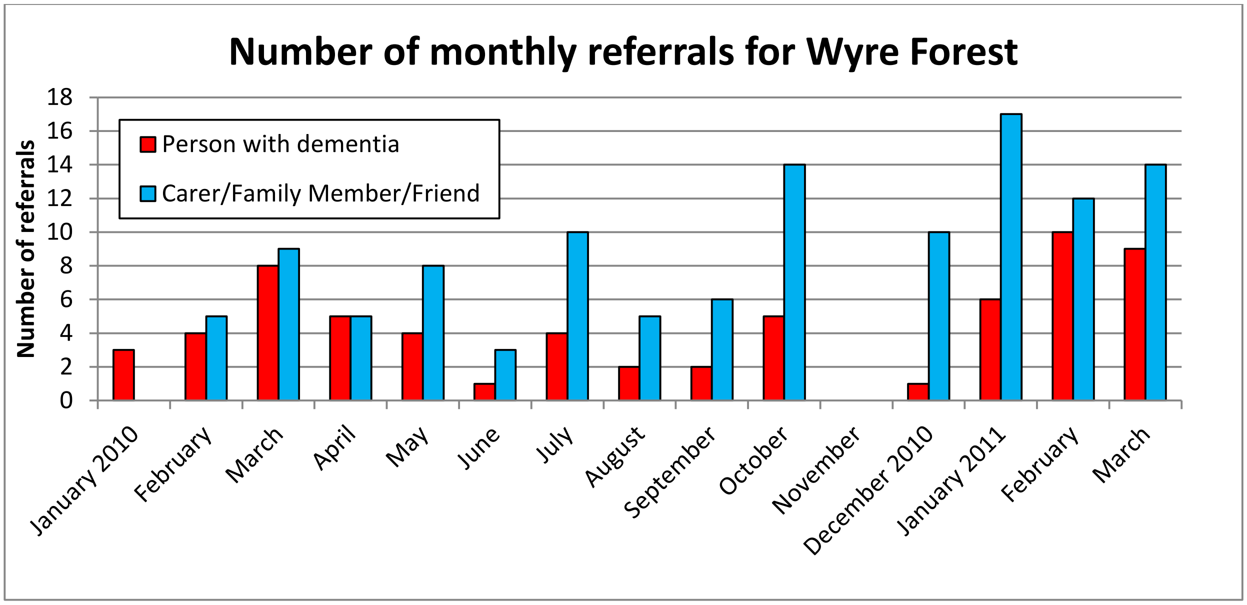

Figure 1: *Month-by-month breakdown of the referrals in Wyre Forest*

6.3.1 Redditch & Bromsgrove

It should be noted that prior to July 2010, the number of referrals was for Redditch only, as the DA was not allocated Bromsgrove until late June 2010.

From Figure 2 it can be seen that it took two months for referrals to start coming through to the DA in Redditch & Bromsgrove; the inclusion of Bromsgrove in July did not initially increase the number of referrals. Consequently it is evident that referrals remained at a fairly low level (5 or less) until January 2011. This reflects the DA experience in this area, of a much longer process of raising awareness and embedding the service. The referrals for family members/ supporters involved in caring outnumber the referrals for people living with dementia and have remained consistently high since October 2010.

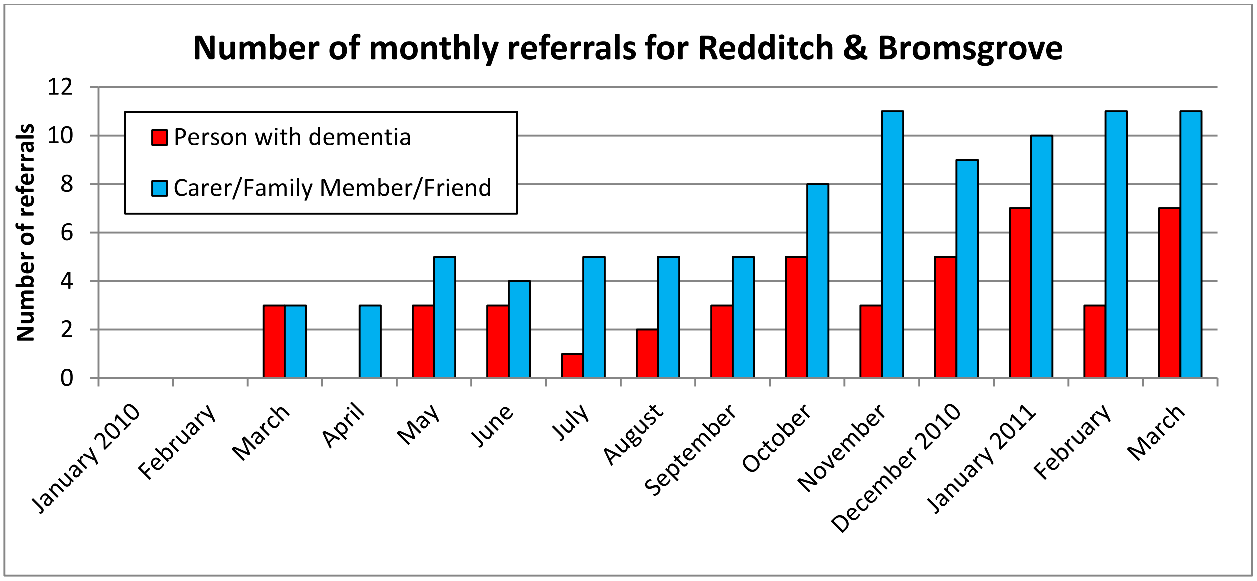

Figure 2: *Month-by-month breakdown of the referrals in Redditch & Bromsgrove*

6.3.2 Overall comparison of the two DA areas

In Figure 3 the referrals for people living with dementia and the referrals for family members/ supporters who are caring are counted together, and compared for the two DA areas. It can be seen that before November 2010 Wyre Forest had more referrals nearly every month, and was quicker to start getting referrals through than Redditch & Bromsgrove. A monthly comparison is difficult from September-December 2010 due to the combination of issues with the Wyre Forest DA and the inclusion of Bromsgrove as mentioned previously. Since the DA Service stabilised in 2011, it has again had more referrals than Redditch & Bromsgrove. This appears to reflect the DA experience, that Wyre Forest appeared to understand the role of DA and had a higher level of awareness of the value of such a role. However within Redditch, the DA's view was that there was a lower level of awareness among the general population and among professionals of dementia and therefore of the value of a role of DA.

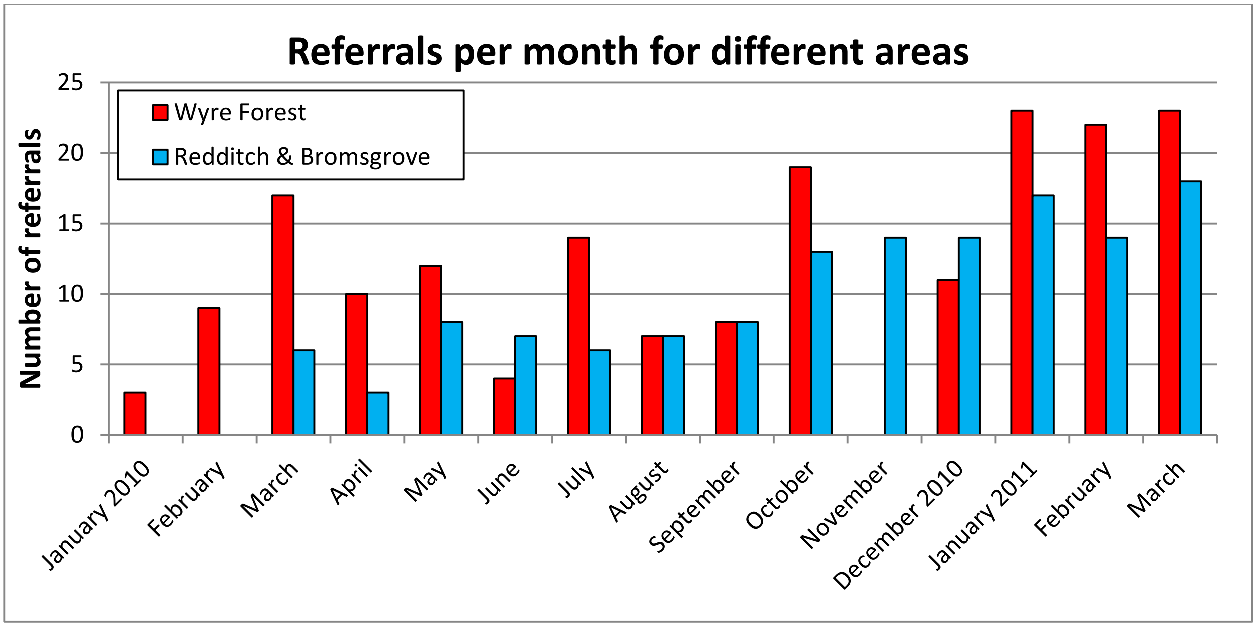

Figure 3: *Month-by-month breakdown of referrals*

Figure 4 provides a comparison of the total number of referrals in each DA area, not just those with a recorded referral date. It can be seen that Wyre Forest has had a greater number of referrals for both people living with dementia (n. 65) and family members/ supporters (n.125) involved in caring, and the DA in both areas have had more referrals for family members/ supporters involved in caring (n. 219 FM and n. 110 plwd).

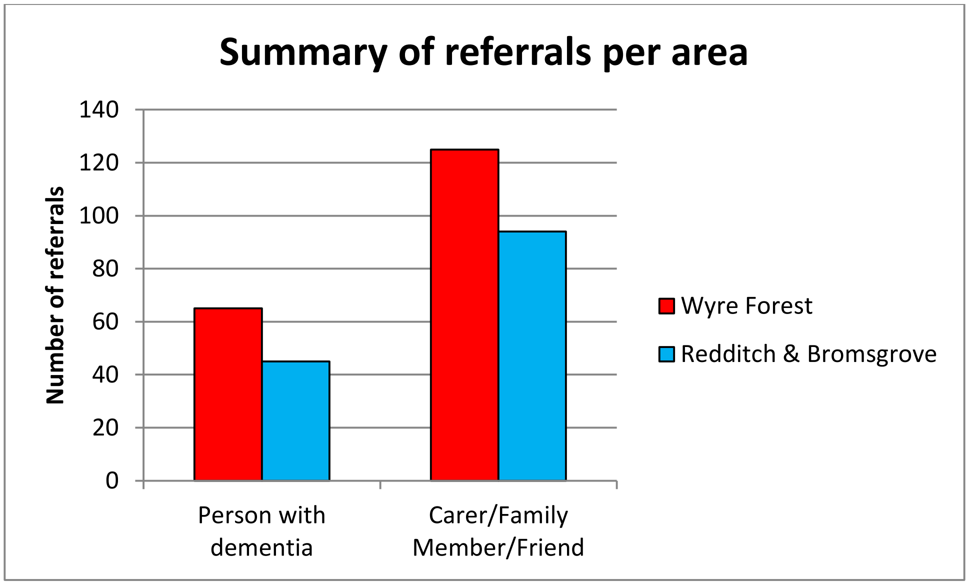

Figure 4: *Total number of referrals*

6.4 Referral demographics

Having seen in the previous section that both DA are getting a steady number of referrals every month, this section considers the referrals from a range of different demographic perspectives. This should provide a better understanding of the people being referred to the DA service, and could identify any areas where more work is required or any issues that the DA should be aware of.

6.4.1 Age

The age profile of people living with dementia who have been referred to the DA Service can be seen in Figure 5, and indicates that the majority of referrals are for those over the age of 75.

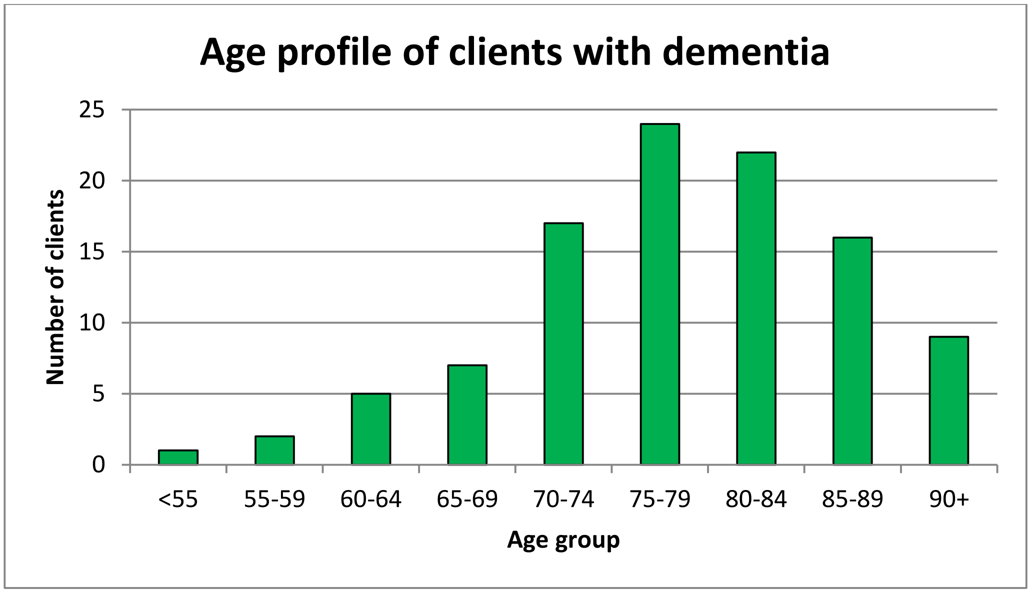

Figure 5: *Breakdown of referrals for people living with dementia by age*

6.4.2 Gender

The referrals have been split into male and female as shown in Figure 6. It indicates that although the split for people living with dementia is fairly even, family members/ supporters are nearly twice as likely to be female as they are to be male.

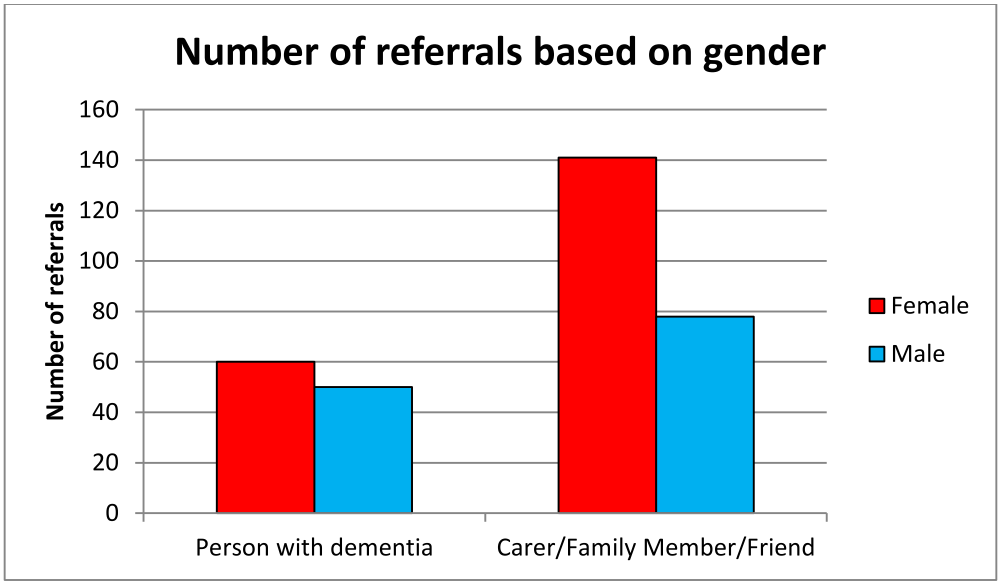

***Figure 6:** Breakdown of referrals by gender*

6.4.3 Ethnicity

Figure 7 shows the ethnicity of referrals for people living with dementia, and clearly illustrates that this information is not known or recorded for nearly half of referrals. The level of unknown ethnicity is even higher for carer referrals at over 60%, as can be seen in Figure 8. In both cases, the information that is available shows that there is virtually no ethnic diversity amongst referrals. More consistent recording would allow an in-depth understanding of whether the DA Service is reaching out to the populations of black and minority ethnic communities within the localities.

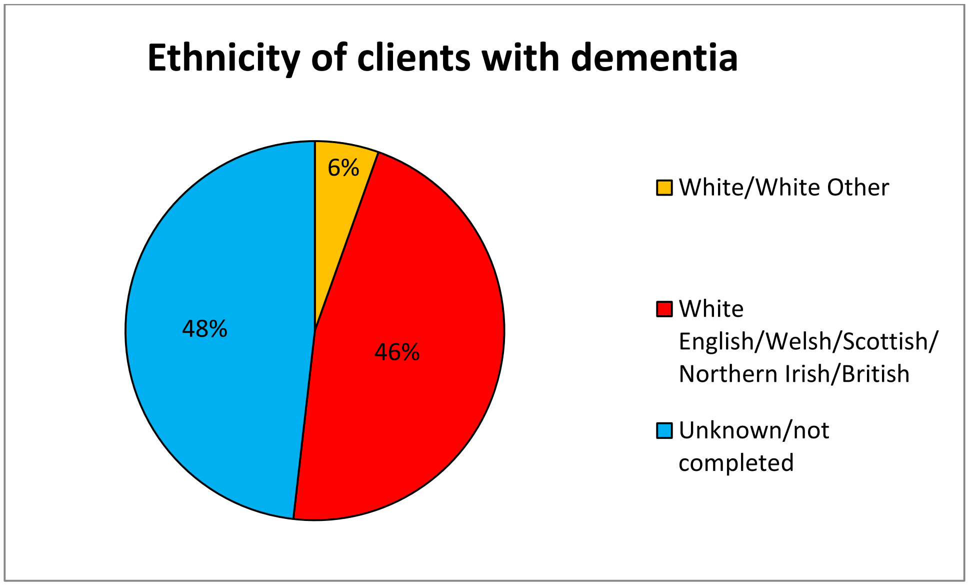

***Figure 7:** Breakdown of referrals for people living with dementia based on ethnicity*

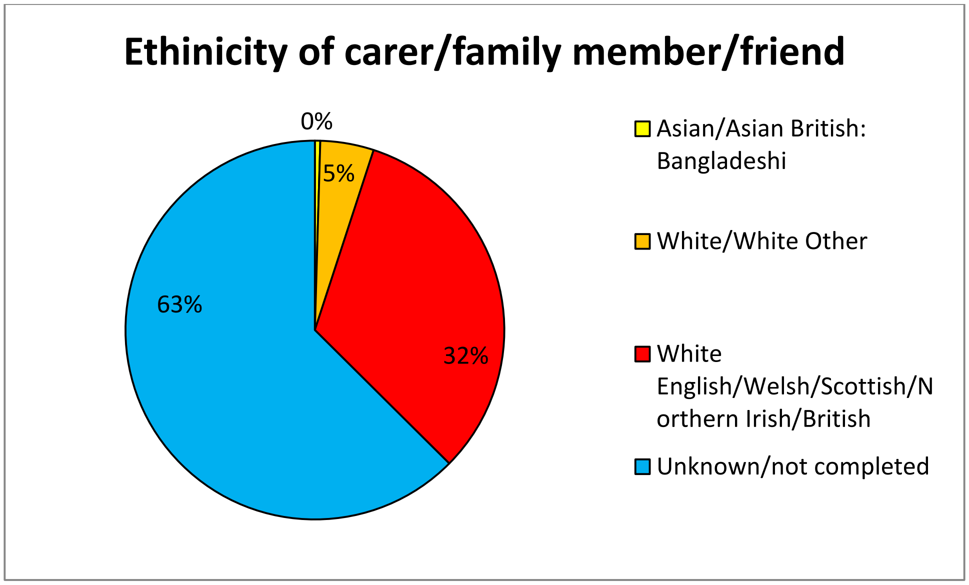

Figure 8: *Breakdown of referrals for family members/ supporters based on ethnicity*

6.4.4 Other disabilities

The presence of other disabilities was unknown in nearly 80% of referrals for people living with dementia, but Figure 9 shows the cases where the information was captured. Although the numbers are very low, they confirm that people living with dementia referred to the service have a range of additional disabilities to contend with. Such disabilities are likely to impact upon the type of services that may or may not be appropriate to signpost on to.

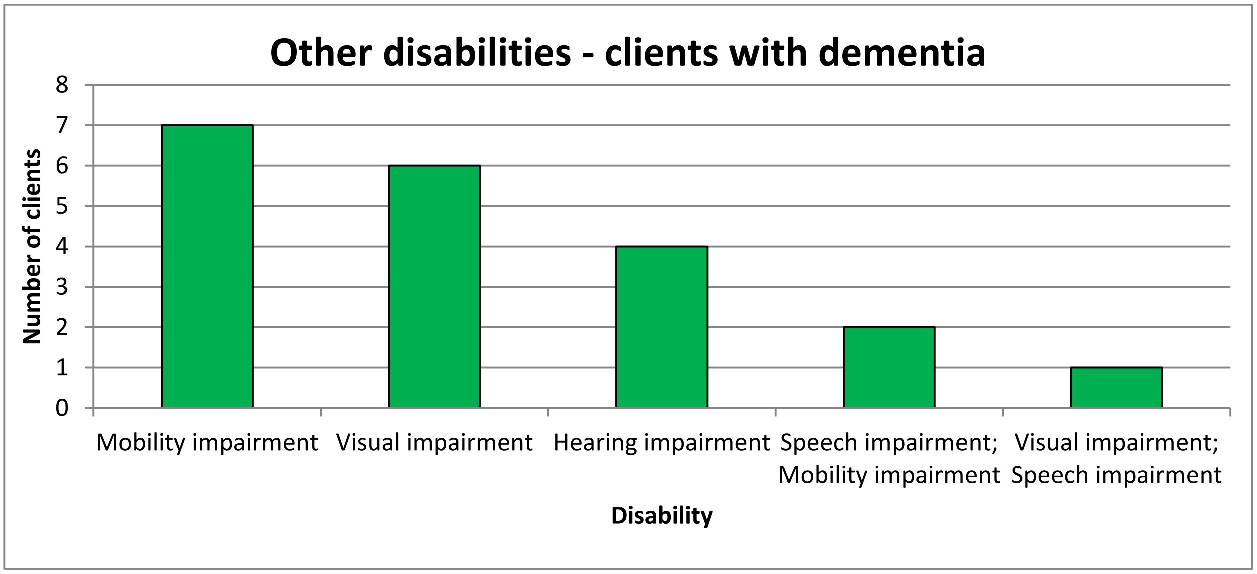

Figure 9: *Breakdown of referrals for people living with dementia based on disability*

6.4.5 Type of dementia diagnosis

Figure 10 shows the dementia diagnosis for referrals, separating them into male and female referrals. It can be seen that the most common diagnosis for both men and women is Alzheimer's disease, although for men, vascular dementia is also quite high. The graph also illustrates the range of diagnoses that the referrals may have, and therefore the different types of dementia that the DA need to know about.

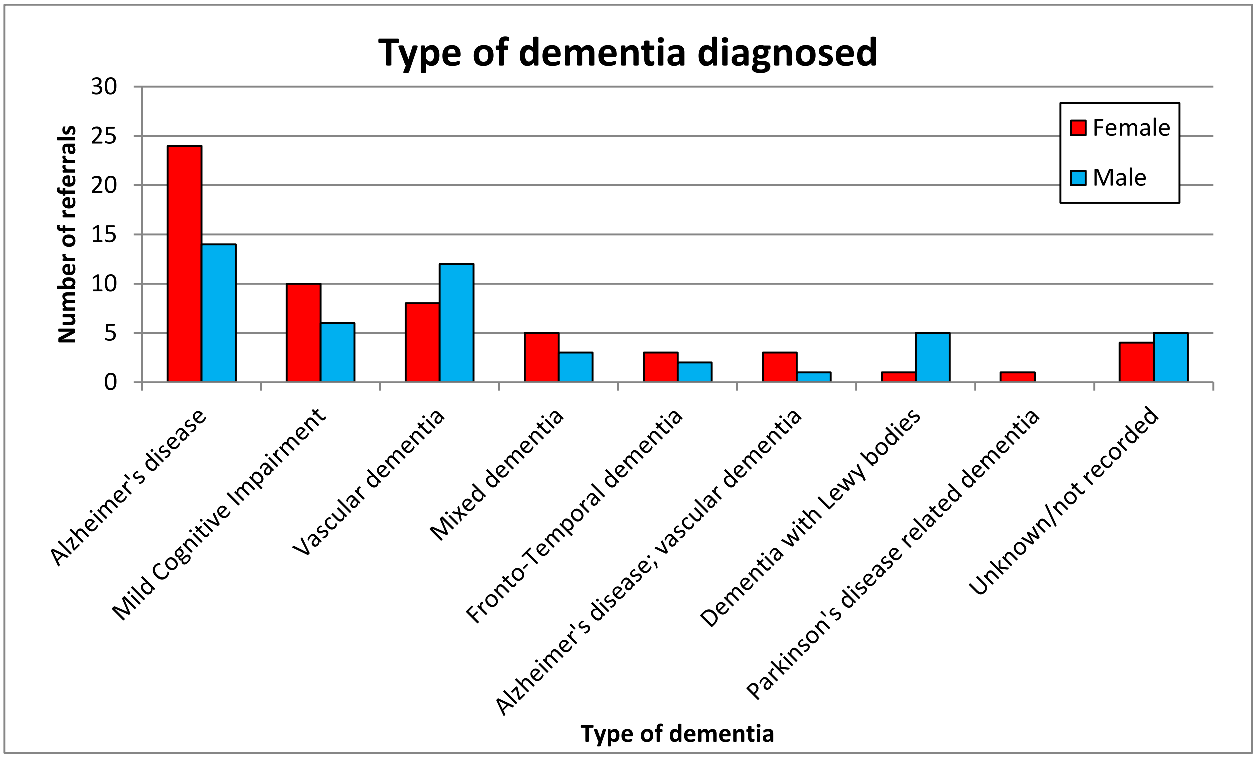

Figure 10: *Breakdown of referrals for people living with dementia based on dementia diagnosis*

6.4.6 Marital Status

The marital status of referrals to the DA Service was unknown or not recorded in around 100 cases, but the referrals where it was recorded are shown in Figure 11. The majority of referrals where marital status is recorded are for married people. As around a third of people living with dementia live alone at home, further data is required to assess the numbers of people accessing the service who live alone, and thus whether this is an under-represented group in terms of referrals.

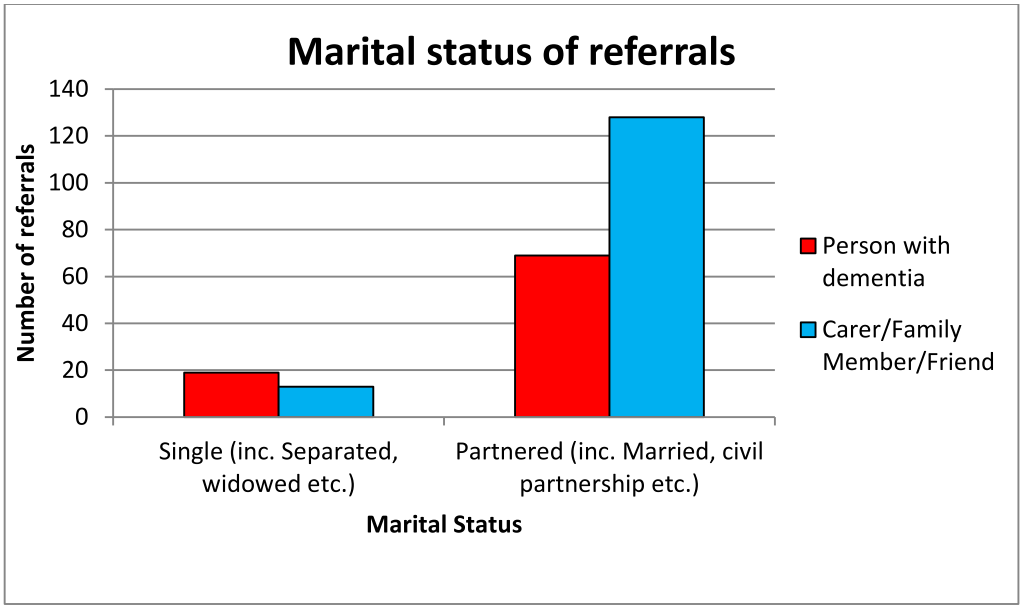

Figure 11: *Breakdown of referrals based on their marital status*

6.4.7 Relationship of family member/ supporter to person with dementia

Following on from marital status, Figure 12 illustrates how family members/ supporters are related to the person with dementia. A total of 70% of are the spouse or partner of the person with dementia, with a further 28% being their adult child or adult child in-law. It is possible that the numbers of referrals for adult children reflects an indirect delivery of the service to people living with dementia living alone.

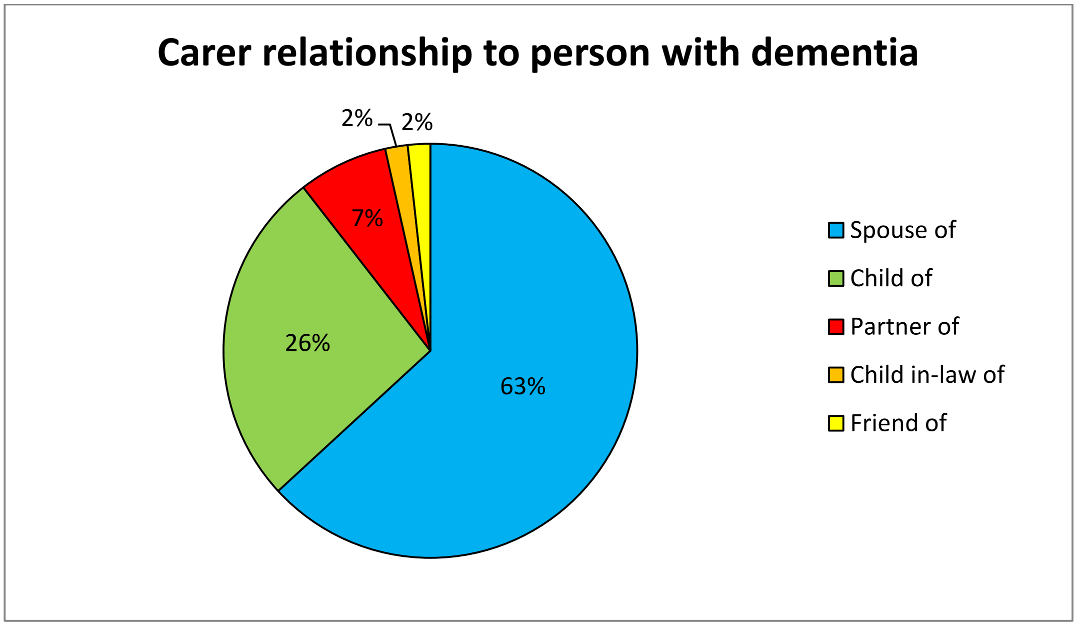

Figure 12: *Breakdown of how carer is related to the person with dementia*

6.4.8 Living arrangements

As with some of the earlier demographic information, the living arrangements were not captured for around half of the people living with dementia referred to the DA Service, but Figure 13 shows the information that was available. It can be seen that in nearly all cases the person with dementia was living in their own home.

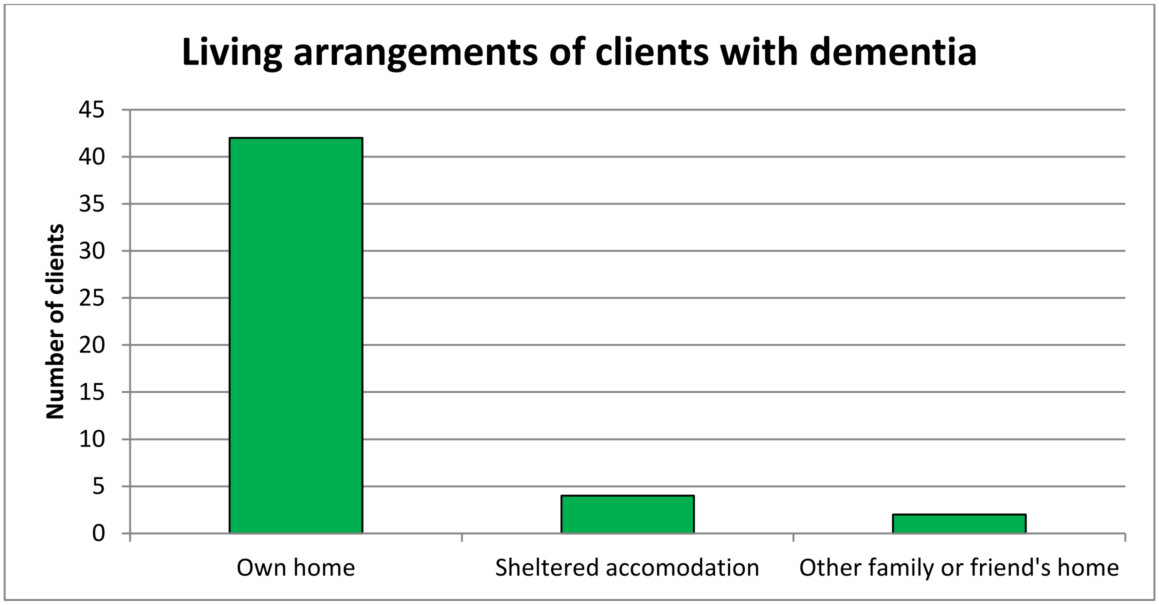

Figure 13: *Breakdown of referrals based on the living arrangements of the person with dementia*

6.4.9 Households

Taking Figure 14 together with Figure 11, Figure 12 and Figure 13, people living with dementia who are referred to the DA Service are most likely to be married and living with their partner, who is also their main supporter.

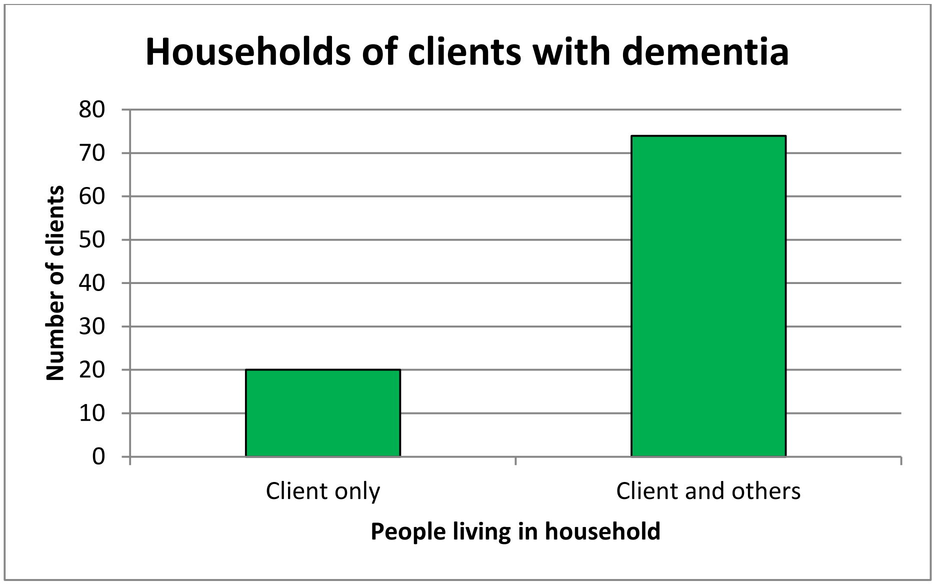

Figure 14: *Breakdown of referrals based on the households of the person with dementia*

6.5 Source of referrals

This section considers the groups and organisations that are referring people to the DA Service, which should show where the service has and has yet to be adopted.

As can be seen in Figure 15, people living with dementia are most likely to be referred by the Early Intervention Dementia Service (EIDS) or the Mental Health Trust. Although referrals for family members/ supporters from these two organisations are also high, the majority of family members/ supporters self-refer to the DA Service. The overall picture shown by Figure 15 is that a wide range of groups and organisations are aware of the DA and are actively referring people to them. The primary referral sources reflect the decisions made early in the implementation of the DA, to achieve referrals from the Mental Health Trust and when established the EIDS.

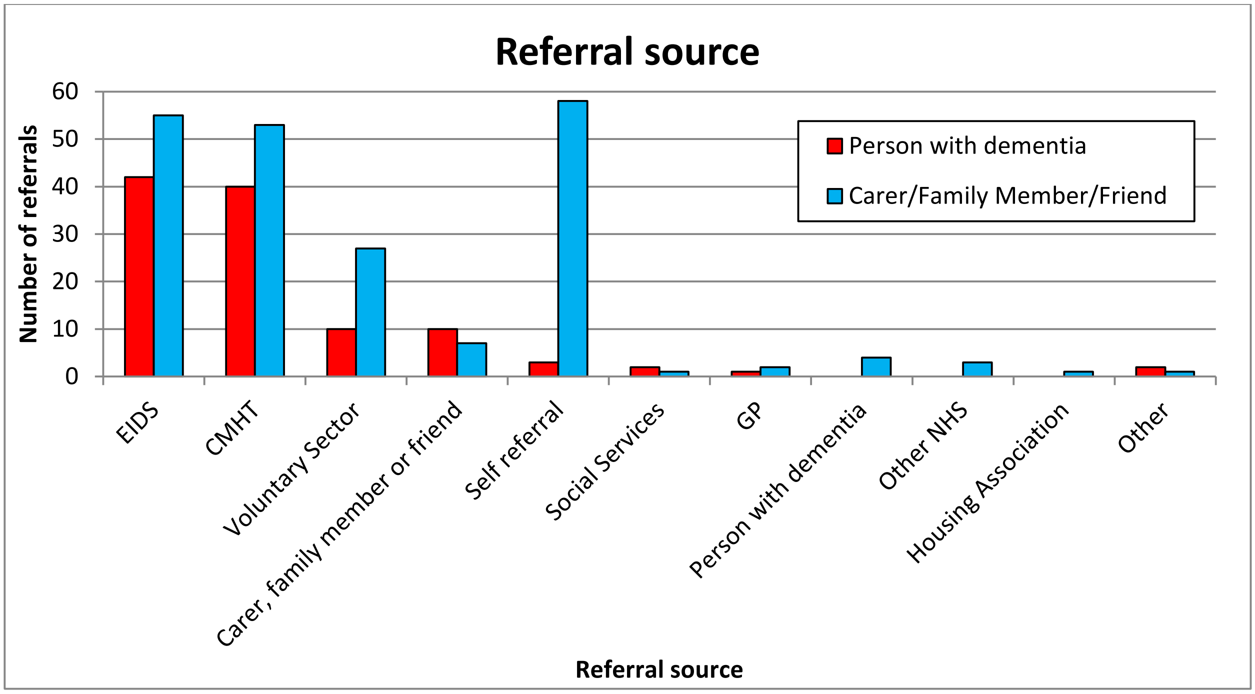

Figure 15: *Breakdown of referral sources*

6.6 Referral activity

The final element of the DA Service which is covered in this section is the actual contact activity that takes place between the DA and the person referred to them. This section considers what form the contact takes, what information is provided by the DA, and where the person if signposted on to. This should provide an indication of what the DA role involves and what parts of the service are important to the people being referred to it.

6.6.1 Type of contact

The number of contacts made by the Dementia Advisers each month is shown in Figure 16, and demonstrates that in general the number of contacts has increased over time, as the services have become more established. The dip during November and December 2010 reflects the start of the maternity leave for the Dementia Adviser in Wyre Forest, and the inclusion of the Christmas holidays. The range of types of contact indicates the communication and organisational qualities needed by the Dementia Adviser, as they have to be able to arrange and conduct meetings as well as having good oral and written communication skills. The use of phone calls is potentially particularly important, as in many cases it might be the first contact between the Dementia Adviser and the client, so a degree of sensitivity and skill is needed to handle that initial contact in an appropriate manner. Phone calls may also be initiated by the client, requiring the Dementia Adviser to have the knowledge base and ability to think quickly and respond to any questions in a more ‘spur-of-the-moment’ fashion than in a meeting where some preparation is possible.

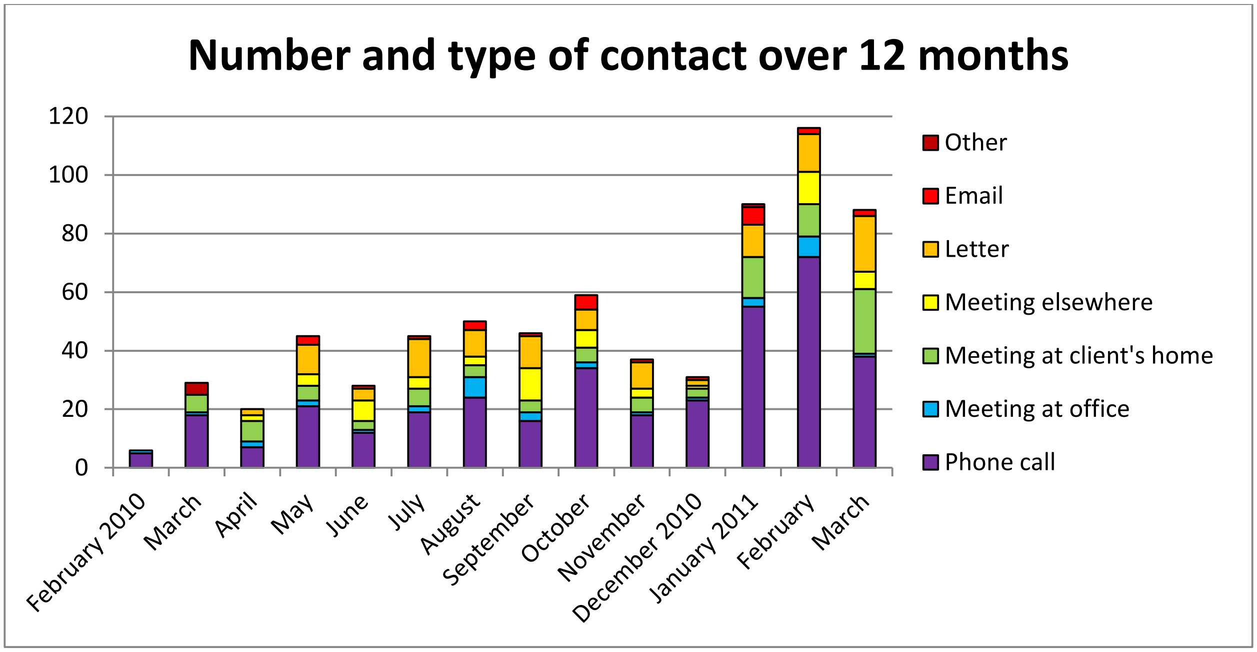

Figure 16: *Breakdown of number of Dementia Adviser contacts*

The different types of contact made by DA are also shown in Figure 17 but this time as a percentage of the overall number of contacts each month. It can be seen that phone calls are the main form of contact between DA and referrals, accounting for anywhere between 35% and 83% of contacts each month. Meetings, in a variety of locations, are also an important type of contact for DA. Figure 18 shows that over half of all contacts were phone calls, with a further 27% of contacts being meetings in different locations.

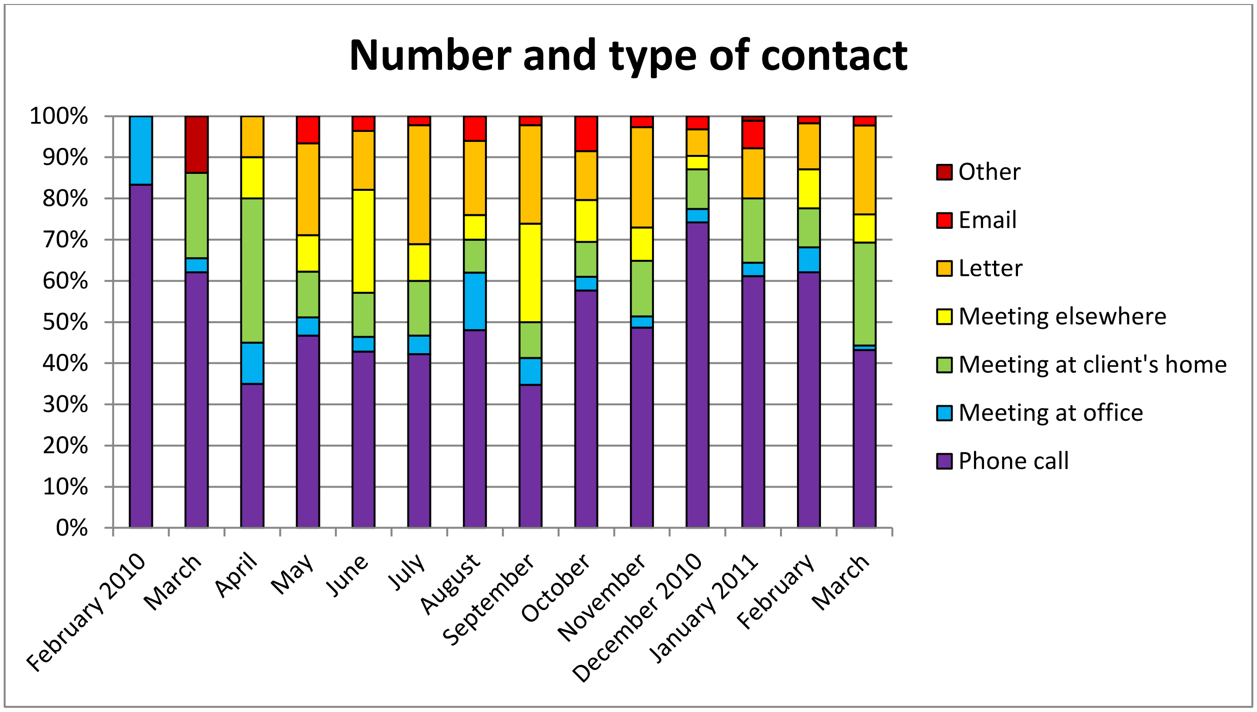

Figure 17: *Breakdown of type of Dementia Adviser contact*

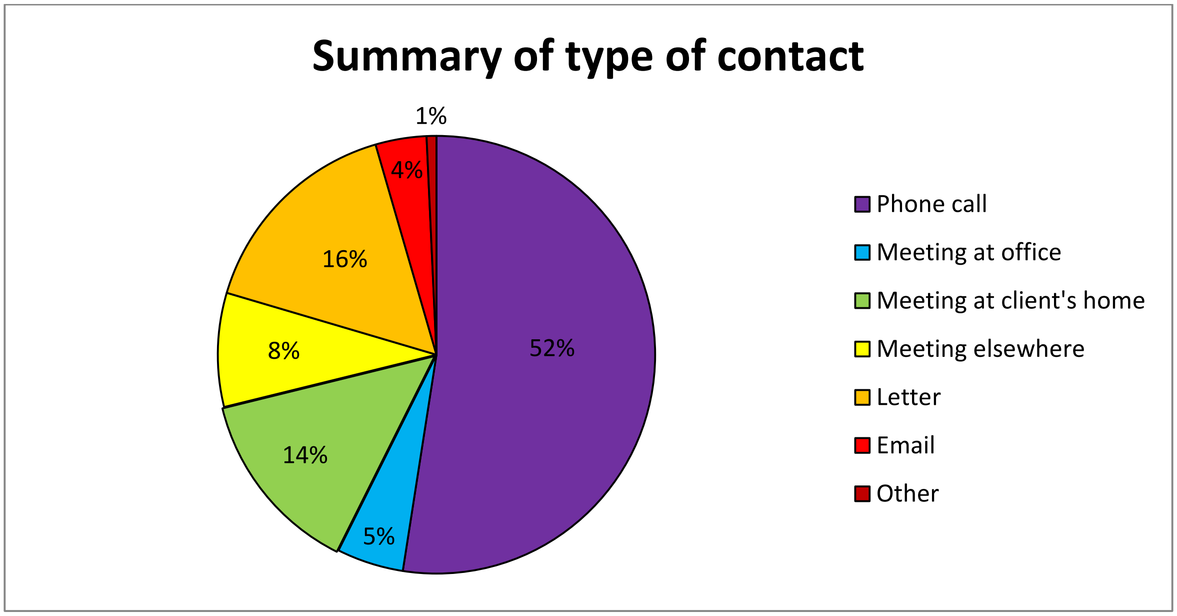

Figure 18: *Summary of type of Dementia Adviser contact*

6.6.2 Duration of contacts

The average duration for each type of contact is shown in Figure 19. Taken in conjunction with Figure 18 it shows that most DA contacts are phone calls, with an average duration of less than 20 minutes. However, due to the large number of phone calls that the DA make, they account for a significant proportion of their time. Similarly, meetings form a significant proportion of the Dementia Adviser role because although fewer of them take place, they are the most time-consuming type of contact with average durations of 55-78 minutes. These durations suggest that the meetings are in-depth and involved which is reflected in the Dementia Adviser's discussions about their work.

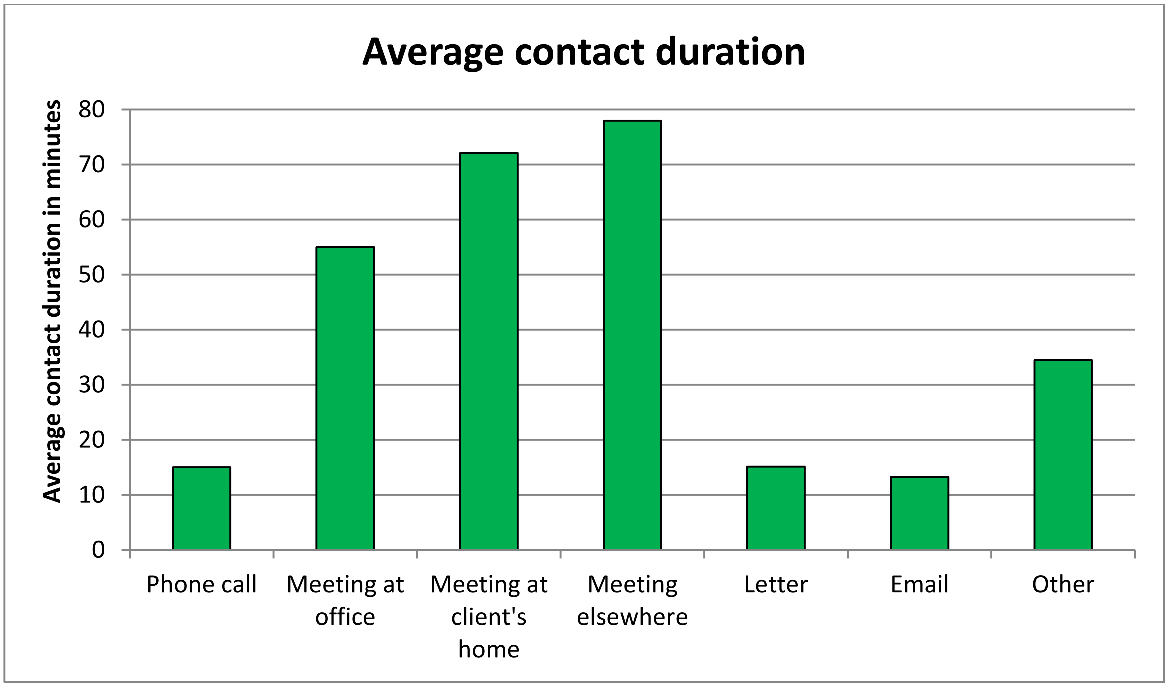

Figure 19: *Summary of duration of Dementia Adviser contacts*

6.6.3 Type of information

During the different contacts, the DA provide information on a whole range of different topics as can be seen in Figure 20. The most common type of information provided is about the dementia diagnosis, but the variety of other topics indicates that the DA have to know about a much wider scope of dementia-related issues beyond those that are just medical.

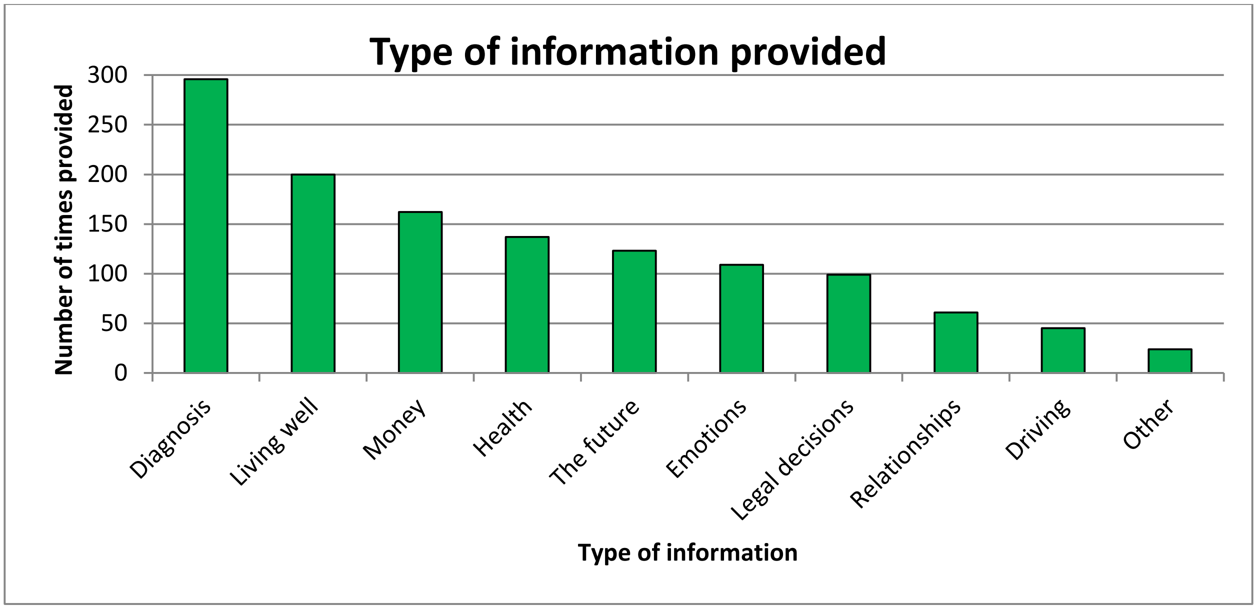

Figure 20: *Type of information provided by the DA*

6.6.4 Services referrals are signposted to

In addition to providing information, DA also signpost people living with dementia and their family members/ supporters to other services. Figure 21 shows the services to which DA have signposted people on more than 20 occasions, and it can be seen that three of the main services accounting for a third of all signposting activities are Alzheimer's Society (AS) services. However, the high percentage of referrals to services covered by the 'Various' section indicates that the DA need to be aware of a wide range of services available in their area.

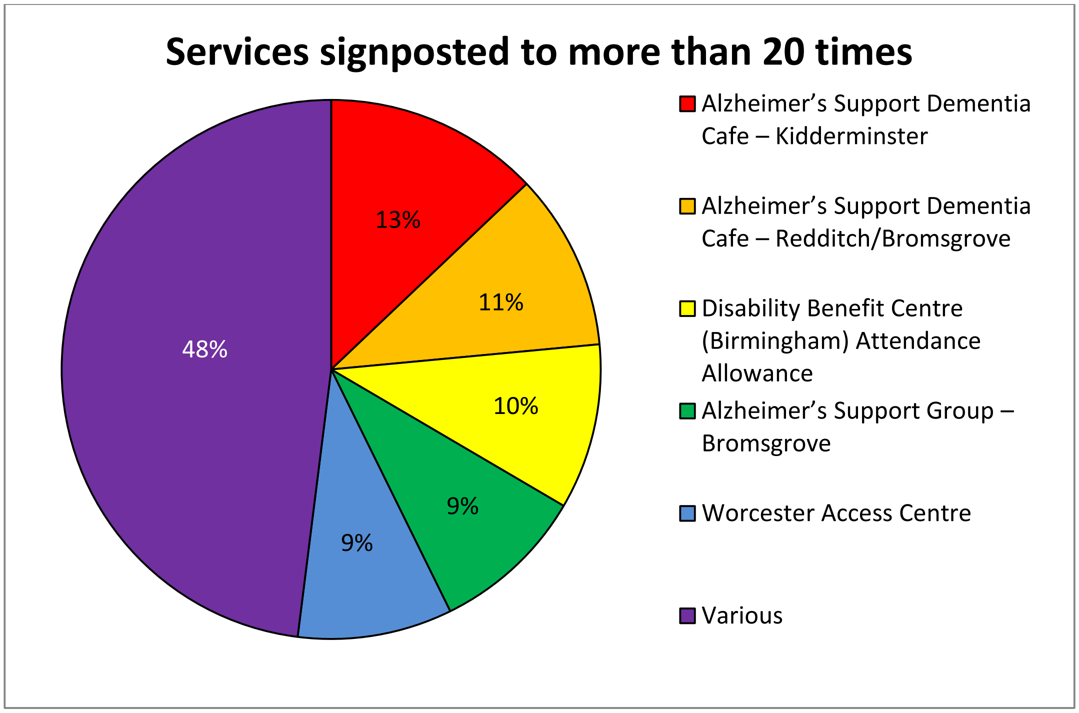

Figure 21: *Services referrals are signposted to by the DA*

Figure 22 considers the signposting activities from a slightly different perspective, by grouping together services of a similar type and seeing how often people are signposted to those types of service. It can be seen that Dementia Cafes are the main type of service that DA signpost to, with a number of different types of support group also well-represented. The variety of types of service again illustrates that the DA need a wide knowledge base of what is available in their area in order to be able to provide a useful service.

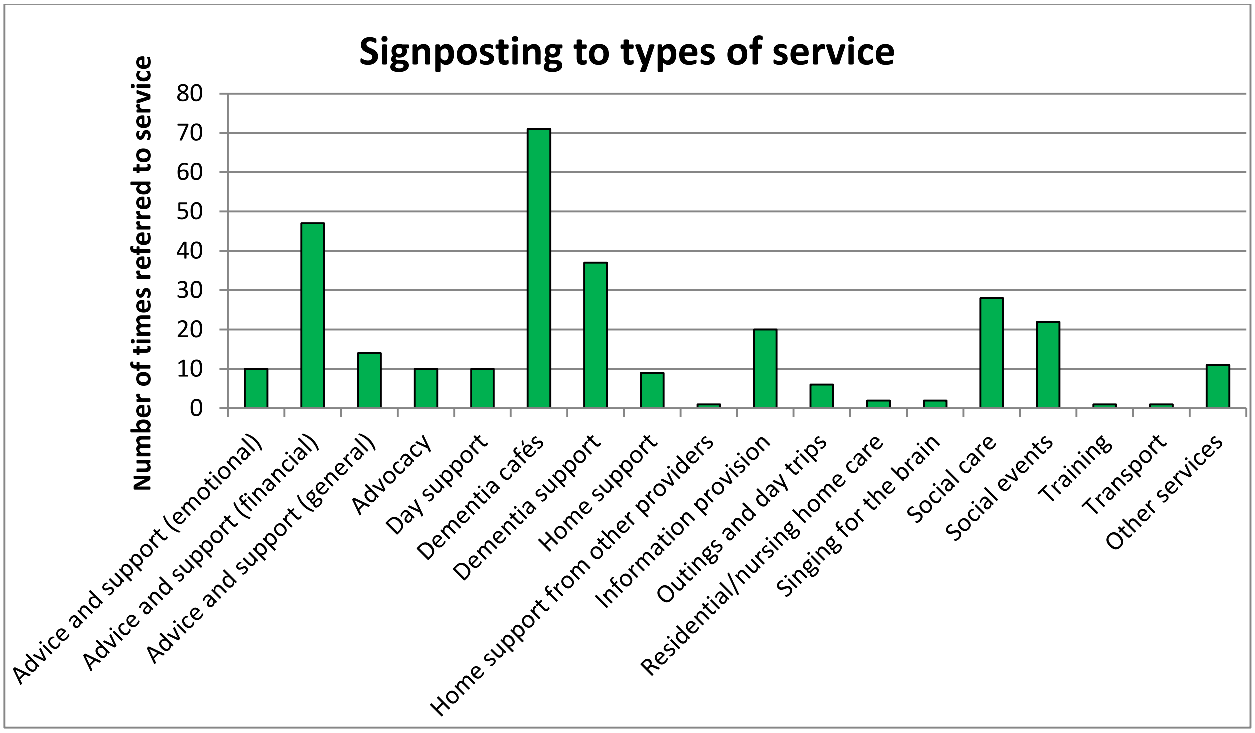

Figure 22: *Type of services referrals are signposted to by the DA*

6.7 Summary

Data from service use indicates the following:

- A total of 329 referrals were received by the DA during the demonstrator pilot, 190 for Wyre Forest and 139 for Redditch and Bromsgrove;
- Redditch and latterly Bromsgrove were later in initiating referrals than Wyre Forest and referred consistently lower numbers throughout the pilot;
- Of those referrals:
  - 110 were for people living with dementia
  - 219 were for family members/ supporters
- 71 of the people living with dementia referred were aged 75 and over;
- 65 of the people living with dementia were female, 45 were male;
- 141 were female family members/ supporters and 78 were male.

Further demographic data is incomplete but the data available shows that:

- Ethnicity of person living with dementia, 48% not completed, 46% white, 6% white/ white other;
- Ethnicity of family member/ supporter, 63% not completed, 32% white, 5% white/ white other;

- Other Impairments, Majority not completed, n.7 had mobility problems, 6 sight difficulties, 4 hearing difficulties;
- The most common diagnosis was Alzheimer's disease (n.38), followed by Vascular Dementia (n.20) and Mild Cognitive Impairment (n.16) 33 were recorded as other forms of dementia;
- Marital status was incomplete but in those recorded, 20 people living with dementia were married, 69 were single, and in family members/ supporters 13 were single and 128 were married;
- 63% of referrals for family members as carers were spouses, 26% were adult children, 7% were partners;
- Regarding living circumstances, only 48 referrals were recorded, but of those 42 lived in their own home;
- Of the 94 recorded, 20 lived alone and 74 lived with partner/ spouse/ family member.

Regarding the source of referrals, the majority of referrals came from EIDS:

- EIDS 42, persons living with dementia and 55 family members/ supporters;
- CMHT, 40 persons living with dementia and 53 family members/ supporters;
- Voluntary Sector, 10 persons living with dementia and 27 family members/ supporters;
- Carer/ family member, 10 persons living with dementia and 7 family members/ supporters;
- Self referrals, 3 persons living with dementia and 58 family members/ supporters;
- Only 3 referrals were received from Primary Care.

Contacts

- The most common form of contact with recipients of the service was telephone contacts which lasted up to 20 minutes;
- The next most common form of contact was meetings, which lasted between 55 and 78 minutes and accounted for 27% of all contacts.

A breakdown of the information topics provided by DA is shown in Table 14.

Table 14: *Information topics provided by DA*

Topic	Number of times
Diagnosis	296
Living well	200
Money	162
Health	137
The Future	123
Emotions	109
Legal Decisions	99
Relationships	61

Signposting

- The service most commonly signposted to by DA was the Alzheimer's Society (32%)
- The disability benefits centre was the next most common at 10%
- The access centre for social care referrals was the next most common at 9%

From analysing the referral information recorded by the DA it can be seen that the people using the DA Service tend to be older, white, married people living at home with their partner who is also their carer, although this is based upon data which is incomplete in some aspects. further information is needed on the extent to which the DA are responding to diversity within the population, and in particular are accessing hard to reach groups such as those living alone and those who are from different ethnic communities within Worcestershire.

The higher number of carers seen by DA may reflect referrals for people whose diagnosis was given some time ago, and/ or who are later in their journey of dementia, but this warrants further exploration/ recording in the database in order to understand the nature of the referrals received by DA, possibly by recording details of the date of diagnosis and length of time experiencing dementia for the person that they care for. This could contribute to a better understanding of the reasons why the service receives more referrals for carers than people living with dementia.

The sources of referrals indicate that although EIDS commenced referrals later, they are the primary source of referrals to the DA, closely followed by the CMHT's. This reflects the alterations that had to be made as a consequence of the different commencement dates of DA and EIDS. It is interesting to note that a significant proportion of self referrals are family members in care giving roles.

The nature of the contacts that the DA have indicate that telephone contacts are their most frequent form of communication with recipients of the service, however although meetings are less common, they take a considerable amount of time.

In regard to the role of the DA, the data indicates that their role is very varied and requires a range of skills. A DA needs:

- To be able to work with people of all ages and at different stages in their journey through dementia;
- Knowledge of at least the main types of dementia;
- To take other disabilities or conditions into account when signposting to other services;
- To work with both the person with dementia and their carer/ family and balance their needs;
- Strong communication and organisational skills;
- To be able to adapt and think quickly;
- Knowledge of a wide range of topics relating to dementia, not just dementia itself;
- To be able to work with a range of referring groups and organisations;
- Good knowledge of the services available in their area;
- Telephone communication skills;
- To be able to communicate with a range of different professionals and organisations.

6.8 How the DA Service has changed

The number of referrals to the DA Service was fairly low during the first few months, suggesting that in particular in Redditch, it has taken a long time for others to understand the role and refer to the DA. Referrals gradually picked up towards the end of 2010 and have remained steady at this higher level for the first few months of 2011.

The range of referring groups and organisations suggested that awareness of the DA Service has spread and improved over time.

The number of contacts that the DA have with their clients has increased over the months, and is higher than the number of referrals. This reflects the nature of the DA role as they can have multiple contacts with the same client during their journey with dementia, showing that they provide an ongoing service.

Chapter 7: Was it a worthwhile investment in improving the service for people living with dementia and their families/ supporters?

7.1 What were the outcomes for people living with dementia, their families and health and care providers?

For People Living with Dementia and their Families
Within the limitations of the data noted earlier, for people living with dementia and their family members, receiving a service from the DA facilitated some specific outcomes for some:

- Greater confidence in the availability of support and who to go to if concerns arise, with the feeling of a connection with the DA and trust in them. This was specifically in the context of joint visits to introduce DA with EIDS and where continuity of service was provided, with regular contact with the DA and being linked in to peer support (where the DA also attended);
- Being able to differentiate what the DA would provide from other potential sources of support;
- Having information concerning dementia and a range of issues associated with their needs, including coping with specific challenges experienced;
- The opportunity to plan for the future, including considering financial and care issues;
- The opportunity to consider current financial issues and apply for entitlements;
- Information about local and county wide services such as the dementia cafes, carers sitting vouchers and how to access social care support;
- Feeling supported emotionally.

The knowledge that support was available was not evident for all participants. This lack of confidence in the support available was specifically evident in those who had only experienced contact via telephone on one occasion; where personal contact had not been established; where ongoing contact had not occurred and where the person in receipt of the service was not linked into joined up services such as the Dementia Cafe. This does however need to be considered in the context of a service which was not designed to provide ongoing contact to families, as those indicating this experience were primarily family caregivers.

The receipt of information concerning dementia and a wide range of issues associated with the diagnosis was valued by people who received the service. However it was important to note that the experience could become overwhelming if it was not delivered with sensitivity and due regard to the needs of the person desiring the information. Thus a blanket approach of giving a large amount of information, as experienced by one of the participants without DA was not helpful. Information concerning living well, finances, entitlements and possible future plans were also viewed as helpful.

Participants identified that they had received information concerning local and county wide services available to them and additionally, how to negotiate those services. However there was an absence of discussion from all participants concerning services which may contribute to quality of life, such as those that would enable the person to engage in meaningful activity. It is likely that there are many factors influencing the absence of a discussion concerning possible services that they could access. It seems possible that one of these factors is the lack of provision of opportunities for meaningful engagement which is appropriately structured to meet the needs of people living with dementia and their families. This may also be a contributory factor in the experience of loss and challenges to adjustment in the follow up interviews.

It has not been possible within this evaluation to establish the impact of the service upon self-esteem, quality of life and the person living with dementia being supported to live at home for longer. This has been for two reasons:

- The number of participants receiving and not receiving a DA recruited to the study was much smaller than originally intended;
- The timescale of the evaluation needs to be longer to measure the impact of the DA.

For Organisations

The length of time it has taken to embed the DA and for referrals to be received, points to the considerable effort that has been required of the DA's in order to establish the value of the service and enable other organisations to understand what their role is. Nevertheless, the experience of organisations concerning the DA has been positive, with the following achievements:

- Increased joined up working with EIDS, thus facilitating continuity of provision through the transition of discharge from EIDS;
- Establishment of partnership working with a range of agencies and professionals, including Admiral Nursing, Carer Support Workers, Community Mental Health Team Staff, Consultant Psychiatrists, Liaison Nurses, Social Workers and Town Hall Advisers;
- Enabling people living with dementia and their families to access service appropriately;
- Providing an ongoing contact point for people living with dementia and their families.

Two primary issues have influenced the achievement of outcomes in this regard:

- In Redditch and Bromsgrove, awareness of dementia within the wider community was low; service provision for people living with dementia has been limited and understanding of the potential value of DA was low prior to and in the early period of the delivery of the service;

- The DA's commenced in post 7 months prior to the Early Intervention Dementia Service. As it was intended that their role would be to work with referrals from EIDS plus some self referrals, the different starting points resulted in the DA having to recruit from a wider referral base, including CMHT's and other agencies and professionals where awareness of their role was less well known and understood.

It is suggested that further work needs to be done as there continues to be challenges in regard to:

- Understanding the exact nature of the work of the DA and how they fit into the established care pathways;
- Raising awareness of the DA including more publicity/awareness of the DA role in groups/services and with wider public;
- Ensuring that joint visits with the Early Intervention Dementia Service to introduce the DA occur, given the different bases of the DA;
- Aligning the service with primary care;
- The availability of services to enable people to live well with dementia as this was identified as a significant barrier to the effectiveness of the DA role.

7.2 What is the experience of the DA, and what's it like to receive their services?

Being a Dementia Adviser has involved the following key aspects to the role, as described by the DA, the people who have used their services and the stakeholders who have worked alongside them:

- Being alongside the person living with dementia and their family in their journey with dementia, which includes making contact with them on a regular basis, dependent upon their needs;
- Carrying out an assessment of need through which the requirements for information and advice, support and signposting can be determined;
- Providing information and advice which is sensitively tailored to the expressed needs of the person in receipt of the service, which can range from:
    - Information concerning dementia itself;
    - Coping strategies for managing specific issues such as understanding the impact of dementia upon behaviour;
    - Living well with dementia;
    - Future planning;
    - Benefits and entitlements;
    - Signposting, which involves the provision of information about local and county wide services that are available and which can also involve assisting the person to access those services as appropriate to their needs;

  - Providing sensitive assistance with planning for the future, including information about finances.
- Promotion of the role and service, and raising awareness about dementia to individuals, groups and organisations within the local community;
- Networking and developing partnerships with key agencies and individual professionals;
- Developing local knowledge so that signposting activities can be carried out effectively;
- Responsiveness to populations who may be hard to reach;
- Identification of unmet need.

Through interviews with the DA, the people living with dementia and their families and those who work alongside them, plus the data on the topics covered in information giving, it is evident that DA require the following skills, knowledge and personal attributes:

Table 15: *Knowledge, Skills and Personal Attributes*

Knowledge	Skills	Personal Attributes
Dementia (different types)	Ability o work independently	Person Centred Value Base
Psychosocial impact of dementia	Interpersonal and Counselling Skills including active listening	Empathy
Experience of living with dementia	Presentation/ Teaching/ Training skills	Resilience
Coping strategies	Problem solving and creativity	Reflect upon their practice
Local Services	Ability to negotiate relationships with a wide range of people	Selling oneself
Sources of information	Time and self management	In-depth experience of working with people living with dementia and their families
Knowledge of family relationships	Flexible and adaptable in their work with others	Openness and approachability
Having a degree	Having a degree	Enabler
	Ability to work with couples and families who may have competing needs	Assertive and confidence in working with a wide range of organisations and professionals
	Telephone communication skills	Creativity

The experience for the DA in delivering the demonstrator pilot has been a challenging one. A range of barriers and facilitators to the effectiveness of the role have been experienced. The barriers have included:

- The preparedness of the area to receive the DA;
- The receptiveness of other services to the role;
- The length of time it took to receive referrals;

- The emotional experience of providing a service to people with complex and emotionally demanding needs;
- Lack of services to enable people to live well with dementia.

Facilitators which have enabled the DA to overcome these barriers have involved:

- Effective management supervision, peer support and supervision, working together and support from other professionals.
  This has provided the DA with the opportunity to reflect, develop confidence and identity and find alternative solutions in challenging situations. Such provision has additionally been identified by stakeholders as important in fostering resilience and coping with the resistance experienced and the emotional impact of working with the experience of people living with dementia and their families.
- Partnership working.
  The identification and development of relationships with key players, who in turn were able to support the development of the role through referrals and promotion of the DA to others was particularly important in enabling the DA to begin to embed the service within the localities.
- Achieving clarity concerning the nature and boundaries of the role.
  Developing this clarity was facilitated through gaining experience of referrals and thus generating case studies which could be used to describe the work of the DA to potential referring agencies. It also enabled the DA to be clear about the limits of their work as well as where they could afford to be flexible.
- Being outside of Statutory Service Provision.
  Being a non-statutory service was an advantage, as experienced by some of the participants who had received a service as well as stakeholders. However it was also at times viewed as a barrier, as some statutory sector staff did not respect their work as a consequence.
- Preparation of the area.
  One of the localities experienced a greater level of preparation for the work of the DA than the other. This preparation included greater level of awareness; greater understanding of the role; greater presence of Alzheimer's Society and an increased level of services. This had a significant impact upon the speed with which referrals commenced and progression of DA into an integral part of the service in the locality.

In spite of the barriers to the role, it is the experience of the Dementia Advisers, many of those who have received a service from them and many of the stakeholders who have worked alongside them that the service is needed and valued.

7.3 Who uses the service, who refers, what interventions occur and what impact does this have on service use?

Data from service use indicates the following:

- A total of 329 referrals were received by the DA during the demonstrator pilot, 190 for Wyre Forest and 139 for Redditch and Bromsgrove;
- Redditch and latterly Bromsgrove took significantly longer to initiate referrals than Wyre Forest and referred consistently lower numbers throughout the pilot;
- Of those referrals:
  - 110 were for people living with dementia
  - 219 were for family members/ supporters
- 71 of the people living with dementia referred were aged 75 and over;
- 65 of the people living with dementia were female, 45 were male;
- 141 were female family members/ supporters and 78 were male.

Further demographic data is incomplete. In particular, the data for ethnicity is recorded only for a small proportion of the referrals. It is therefore difficult to draw any conclusions from this data.

- Where diagnosis was recorded The most common diagnosis was Alzheimer's disease (n.38), followed by Vascular Dementia (n.20) and Mild Cognitive Impairment (n.16) 33 were recorded as other forms of dementia;
- Marital status was incomplete but in those recorded, 20 people living with dementia were married, 69 were single, and in family members/ supporters 13 were single and 128 were married;
- 63% of referrals for family members as carers were spouses, 26% were adult children, 7% were partners;
- Regarding living circumstances, only 48 referrals were recorded, but of those 42 lived in their own home;
- Of the 94 recorded, 20 lived alone and 74 lived with partner/ spouse/ family member.

Regarding the source of referrals, the majority of referrals came from EIDS:

- EIDS 42, persons living with dementia and 55 family members/ supporters;
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- Only 3 referrals were received from Primary Care.

Contacts

- The most common form of contact with recipients of the service was telephone contacts which lasted up to 20 minutes
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A list of the information topics provided by DA are shown in Table 16.

Table 16: *Information topics provided by DA*

Topic	Number of times
Diagnosis	296
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Signposting

- The service most commonly signposted to by DA was the Alzheimer's Society (32%)
- The disability benefits centre was the next most common at 10%
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People using the DA Service tend to be older, white, married people living at home with their partner who is also their carer, although this is based upon data which is incomplete in some aspects. Further information is needed on the extent to which the DA are responding to diversity within the population, and in particular are accessing hard to reach groups such as those living alone and those who are from different ethnic communities within Worcestershire.

The higher number of carers seen by DA may reflect referrals for people whose diagnosis was given some time ago, and/ or who are later in their journey of dementia, but this warrants further exploration/ recording in the database in order to understand the nature of the referrals received by DA, possibly by recording details of the date of diagnosis and length of time experiencing dementia for the person that they care for. This could contribute to a better understanding of the reasons why the service receives more referrals for carers than people living with dementia.

The range of referring groups and organisations suggested that awareness of the DA Service has spread and improved over time. The number of contacts that the DA have with their clients has increased over the months, and is higher than the number of referrals. This reflects the nature of the DA role as they can have multiple contacts with the same client during their journey with dementia, showing that they provide an ongoing service.

The low numbers of signposting activities is consistent with the DA experience of low availability of resources for living well with dementia.

Chapter 8: Key Areas for Further Consideration/ Development

8.1 For direct work with People Living with Dementia and their Families

While the numbers of people living with dementia in the study are small and not representative, their views provide important pointers in moving forwards with the service. These include:

- A joint visit to introduce the service with EIDS does appear to be an effective strategy as it facilitates a clear understanding of the work of the DA and allows personal contact which creates opportunities to establish trust and confidence in the relationship;
- People who are less likely to re-establish contact, and/ or do not avail themselves of peer support are potentially more likely to lose contact and may benefit from a more assertive and regular form of engagement. Although the DA have regularly maintained contact with some who have used the service, not providing an ongoing service to family members has resulted in a loss of continuity for them and as a consequence for the person living with dementia that they care for. This is likely to become more of a challenge for DA as referrals increase;
- Although defined as a service for people with dementia, referrals have been received for family members consistently. This is likely to reflect the reality of people with dementia who have received a later diagnosis or have received little support and who are less able to engage with the service directly. However it also reflects the DA experience that even for those earlier in the journey of dementia, it is occurring in a relational context, either as couples or as adult children and parents. As remaining at home is predicated on family relationships and care giving, particularly as the journey progresses, is it more appropriate to view DA as responding to people living with dementia, a term which encompasses family members who are also living with it. A clear consciousness can still be maintained on providing a service to the person with the diagnosis in this context, particularly as the interests of both parties are not always compatible;
- Associated with the above issue, it would be beneficial to generate data concerning the characteristics of family members as service recipients, including the diagnosis of the person they are caring for and the date of diagnosis;
- Data concerning the extent to which the service receives referrals for hard to reach and vulnerable populations' would benefit from being consistently recorded. Plans may need to be considered to ensure that such groups are able to access the service. This includes people with dementia living alone, people from black and minority ethnic groups, younger people with dementia and people who experience dementia in the context of other disabilities which may impact on their ability to access support.

8.2 For the delivery of Dementia Adviser Services

- Being based with EIDS, having a close working relationship and a shared understanding of the role appears to maximise opportunities for joined up working to occur;
- Publicity and education concerning the role of the DA continues to be needed within specialist mental health services, primary care and the wider community. This will assist in achieving a greater understanding of the role, therefore clarifying when to refer and enable the role to be embedded into the care pathway;
- Dementia Advisers value firmly embedded structures of management supervision, support and peer supervision in order to address their experiences concerning the delivery of the service and to enable them to develop;
- Ongoing education concerning the core facets of their role, and where possible, for this to be collaborative training with other professionals involved in dementia care would be valuable to the Dementia Advisers;
- Preparation of the locality prior to and during the development of the role is an essential requirement to reduce the time it takes to embed the role and to receive referrals;
- Dementia Advisers need to be proficient in regard to interpersonal skills in order to sensitively respond to the needs experienced by people living with dementia and their families;
- Considering the ways in which the job description, person specification and appointment processes can reflect the range of knowledge, skills and personal attributes required of the Dementia Adviser;
- Considering the boundaries of the work of the Dementia Advisers may become important as they receive more referrals and reach capacity. This would seem to be particularly important to maintain their effectiveness;
- Data concerning promotion of the role, awareness raising and networking might usefully be included in data collection to understand the breadth of work undertaken by Dementia Advisers.

8.3 For the Development of Services for People Living with Dementia

- Consideration of how the range of opportunities to meet the needs of people to live well with dementia and their families can be effectively provided with the wider community outside of statutory services, particularly in areas of poor service provision. This will be essential to address quality of life of people living with dementia and in ensuring the success of the role;
- Awareness raising to challenge stigma and labelling which appears in some services to impact upon their willingness and ability to provide services for people living with dementia.

8.4 For Future Evaluation

- It has not been possible to assess some of the outcomes of the service. Future evaluation of the service, which would involve following people living with dementia and their families over time to assess impact upon quality of life, self esteem, coping and ability to remain at home would seem to be an appropriate next step;
- Future evaluation could also consider service use over time, tracking the repeat contacts made with the service and the reasons for this contact, thus developing a deeper understanding of how the contact with Dementia Advisers changes over time and therefore the nature of the work.

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