



*Association for Dementia Studies*

# Evaluation Report Early Intervention Dementia Service Worcestershire

## Prepared for Worcestershire Health and Care NHS Trust

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## **Executive Summary**

### **The Context**

It is estimated that there are currently over 800,000 people in the UK with dementia (Luengo-Fernandez *et al.*, 2010), rising to over 1.5million by 2051 (Knapp *et al.*, 2007). With this significant increase in the number of people living with dementia, the predicted national financial cost is £34 billion per year by 2026 (National Audit Office, 2010). The economic impact of dementia is already substantial with the national cost estimated at £23 billion per year in 2008 and an average cost of over £27,000 for each individual over the age of 65 with dementia (Luengo-Fernandez *et al.*, 2008).

It is widely acknowledged that there is also a profound personal cost to the experience of dementia, for both the person living with the diagnosis and their families. Personal costs include increased risk of admission to institutional care for the person with dementia and poor physical and mental health for the family member providing care (Brodaty, *et al.*, 2007, Banerjee & Wittenberg, 2009.) In spite of the recognition of the significant challenges experienced by people living with dementia and their families, it is suggested that current services frequently fail to provide effective support (National Audit Office, 2007). Indeed, the National Audit Office (2007) estimated that less than half of people with dementia in the UK received a formal diagnosis or had any contact with dementia specific services throughout the course of their illness. Banerjee and Wittenberg (2009) also indicate that the focus for older adult mental health services providing interventions for people with dementia tended to focus on complex and severe cases, resulting in a paucity of attention on early diagnosis and intervention. Furthermore, recent international comparisons have suggested that the UK performs very poorly in terms of diagnosing and treating dementia (Waldemar *et al.*, 2007).

Thus the economic and personal costs of dementia combined with evidence of patchy service provision provide a powerful argument for the need for services to do more to raise awareness of dementia and reduce the stigma surrounding dementia (National Audit Office, 2007, 2010). Such action may increase the likelihood that people seek help and do so earlier to facilitate access to the support and treatment available before a crisis is reached. It has also been suggested that enabling early intervention could have multiple positive outcomes, including a reduction in health care costs, a reduction in negative outcomes in care and an increase in the quality of life of the person living with dementia and their family members (National Audit Office, 2007).

### **The Service**

The provision of Early Intervention Services creates opportunities to maximise choice and autonomy, and assist the person living with dementia and their family/ supporters to adapt to the illness and make plans for the future. An evidence base exists for the provision of services which facilitate early diagnosis, for example Croyden Memory Services, which acted

as a national pilot site for early diagnosis and intervention (Banerjee, et al. 2007, Banerjee, et al. 2009, Willis et al. 2009). Within Worcestershire, the Early Intervention Dementia Service (EIDS) commenced in July 2010. EIDS provides an assessment, diagnosis and early intervention service to people who have suspected early signs of dementia.

The aims of the EIDS are as follows:

- A reduction in time from first symptoms to diagnosis measured by time between initial presentation to diagnosis
- Greatly improved user choice, especially as people with dementia have the opportunity to make decisions about their care before their mental capacity is impaired.
- The provision of the comprehensive and accessible service, focussing on high quality interventions at an early stage.
- An improvement in the quality of life for service users and carers; alongside the enablement of lifestyle choices for the future
- An increased percentage of dementia recorded on primary care Dementia Registers.
- Significant engagement with primary care and others to raise awareness of the value of early intervention, stimulate referrals, reduce negative attitudes to referral and help primary care to develop appropriate skills to work with this group.
- The achievement of a high appropriate referral rate and a high acceptability rate with service users and carers.
- An increase in the overall numbers of new cases of dementia seen.
- Successful engagement with minority groups.

Evaluation of the effectiveness of the service offered is an integral aspect of the work of the service and deemed necessary in order to achieve a high quality service for people with suspected dementia, their families and supporters.

### **The Evaluation**

An evaluation has been completed which comprised of two separate strands:

1. To consider data from all referrals to EIDS from the period commencing July 1<sup>st</sup> 2010 to June 30<sup>th</sup> 2011 with reference to the desired outcomes.
2. To consider the perspectives of people receiving the service, using quantitative and qualitative data

This evaluation plan was expected to assist EIDS to understand the extent to which the service had addressed the outcomes outlined below;

**Table 1 Selected EIDS Outcomes**

<b>1. All people with dementia have access to a pathway of care that delivers:</b> <ul style="list-style-type: none"><li><b>a. A rapid and competent specialist assessment</b></li><li><b>c. A sensitively communicated diagnosis to the person with dementia and their family carers</b></li><li><b>d. Immediate treatment, care and support following the diagnosis</b></li></ul>
<b>2. People with dementia and their carers to be provided with good quality information on the illness and the services available both at diagnosis and throughout the course of the illness</b>
<b>5. Greatly improved user choice</b>
<b>6. Giving people with dementia the opportunity to make decisions about their care before their mental capacity is impaired</b>
<b>7. The provision of a comprehensive and accessible service, focusing on intervention at an early stage</b>
<b>8. Significant engagement with primary care and others to</b> <ul style="list-style-type: none"><li><b>a. Raise awareness of the value of early intervention</b></li><li><b>b. Stimulate referrals</b></li><li><b>c. Reduce negative attitudes to referral</b></li></ul>
<b>9. Achievement of a high appropriate referral rate</b>
<b>10. Achievement of a high acceptability rate with clients</b>
<b>11. An increase in the overall number of new cases of dementia seen</b>
<b>12. Successful engagement with minority groups</b>
<b>13. An improvement in the quality of life for users</b>
<b>14. An improvement in the quality of life for family members/carers</b>

## The Main Findings

### Qualitative evaluation to explore the perspective of people using the service and their families

- **Referral to EIDS through GPs:**

Although some of the couples found referral to EIDS straightforward, others had problems, due to GPs not taking them seriously, communication difficulties, or the person experiencing difficulties not wishing to accept there was a problem. Family members were often put under severe strain during this period.
- **Meeting the EIDS nurse:**

Most spoke highly of their first meeting; appreciating the quick response, being listened to and feeling reassured, and receiving a clear explanation of the EIDS service.
- **Assessment:**

While a number were reassured by the welcoming and calm manner of the staff, the tests were stressful and tiring for some of the people experiencing difficulties, and some people felt shocked at discovering their own or their partner's difficulties.
- **Diagnostic disclosure:**

People experienced shock when they received a diagnosis and relief if no disorder was found. However, there was also relief for people receiving a diagnosis with regards to knowing what they were dealing with. This was experienced strongly among family members. The staff were praised for their handling of this stage by a number of the participants.
- **Treatment and support:**

A large proportion of the participants greatly appreciated ongoing support and contact with EIDS staff after assessment. Some received practical support and advice and some attended the Living Well with Dementia day and appreciated the information and contact with other couples. The Dementia Adviser service was viewed positively by a number of the participants though a small proportion of people had a less positive experience. Two of the people who were discharged from the service were a little concerned about lack of follow-up.

The overall view of EIDS was overwhelmingly positive, in terms of professionalism and person-centredness (choice, information, advice, respect, warmth, support and empathy).
- **Has EIDS made a difference to people's lives?**

A number of the participants reported very positive, even dramatic improvements in the lives of persons experiencing difficulties, including increased well-being, confidence and independence, and adoption of helpful coping strategies. Family members also reported improved well-being in their own lives, and said that the intervention had improved their couple relationships and general morale. Although there were still concerns about the future among those who had received a diagnosis, there was a sense that they had

gained resources and knowledge to enable them to adapt, stay positive and cope better than before.

- **Recommendations for the future of EIDS:**

None of the participants had any improvements to suggest, since most found the service exemplary. The main hope expressed was for EIDS to become more widely known and available across the country for others who would need it.

### ***Satisfaction with the Service***

Following the qualitative interviews, people experiencing difficulties and their family members were asked to complete a range of questions concerning satisfaction with the service. These included questions concerning the following issues:

1. Length of time between appointments (Question 1)
2. Number of appointments (Question 2)
3. Quality of information (Question 3)
4. The way in which information was delivered (Question 4)
5. Emotional Support (Question 5)
6. Concerns listened to (Question 6)
7. Level of control (Question 7)
8. Amount of written information (Question 8)
9. Overall Satisfaction (Question 9)
10. Recommend the service (Question 10)

The majority of participants were highly satisfied with the service in answer to all of the questions. A small proportion answered satisfied, with only 3 giving a neither satisfied or dissatisfied response. No one expressed dissatisfaction. Overwhelmingly participants would recommend the service to someone they knew and felt that it should be widely available.

### ***Data Concerning Service Use***

#### **All Referrals**

- 683 referrals were received during the period July 1<sup>st</sup> 2010 to June 30<sup>th</sup> 2011.
- Malvern had the lowest referral rate, which is not consistent with the prevalence of dementia in the locality
- 96% of referrals were from GP's but the numbers redirected from CMHT were not recorded on the database, recording this would assist in facilitating understanding of raised awareness in primary care
- 108 referrals were rejected, the majority of these were early in the year, however an increase in rejected referrals occurred in May and June 2011 which coincided with a change in referral processes. An even spread of rejections was noted across the localities. The majority of those referrals rejected were for complex needs and were referred to CMHT

- Only 12 people declined an appointment before first visit. Given the stigma associated with dementia, this represents a very small proportion of the total referrals received by the service.
- The demographic breakdown of accepted referrals is as would be expected, i.e. greater number of women at an older age, over half living with spouse and 33% living alone with adult child involved in their care
- Only two referrals were received for people from Black and Minority ethnic groups, although there is missing data concerning this group. There is a need to ensure accurate recording of ethnicity, and to explore ways of ensuring that those people from Black and Minority Ethnic Groups who require an assessment are facilitated to access the service.
- 289 referrals had completed their journey through the service by the 30<sup>th</sup> of June 2011
- Of the 485 who had progressed past their first visit the majority (n. 395,86.8%) chose to accept the service offered
- 395 (86.6%) of people chose to continue with the service following the first visit. 84 people declined to continue with the service following the first visit. A further 6 people declined to continue following assessment (A total of 13.2%). This suggests the service is offering choice, however it would be beneficial to understand in more depth the reasons for those declining the service at these points. This is not currently recorded.
- The time spent at different points in the pathway was identified as follows:
  - The average time taken to progress from acceptance of referral to first visit was almost 5 weeks, although the most commonly occurring time span was 2 to 3 weeks. The range was from less than a week, to 28 weeks. 302 referrals (74.8%) were seen for their first visit within 6 weeks
  - The average time from first visit to assessment was five and a half weeks, but the most commonly occurring time span was 3 to 5 weeks. The range was from under a week between first visit and assessment to almost 27 weeks. 244 referrals (80.8%) commenced assessment within 8 weeks of their first visit.
  - For the time from assessment to diagnosis, the average waiting time was just over 6 weeks, with the most commonly occurring wait of less than a week. The range was from under a week, to over 37 weeks. 192 referrals (77.4%) were seen within 10 weeks of their assessment
  - For the time from diagnosis to discharge, which incorporates interventions, the average time was 7 weeks, with the most commonly occurring frequency of 1 to 2 weeks following diagnosis. The range suggests that whilst some people left the service immediately after diagnosis (n.17) or within 1 to 2 weeks (n.45) over half of those reaching this point experienced a longer period of intervention, lasting from between 2 to 3 weeks up to 6 months. 122 (71.7%) experienced intervention and subsequently discharge within 10 weeks of diagnosis.



A range of different forms of dementia were diagnosed:

- 24.9% did not have a diagnosis of dementia
- 18.4% received a diagnosis of Alzheimer's disease
- 17.7% were informed that they had Mild Cognitive Impairment
- 12.5% received a diagnosis of Vascular Dementia
- 8.8% Mixed Dementia
- 6.4% Dementia with Lewy Bodies
- The remainder (11.3%) were less common forms of dementia
- A gender difference was noted in those who had a diagnosis of dementia without a specified type, or where the diagnosis was Dementia with Lewy Bodies or Frontotemporal dementia. A greater proportion of these were men in comparison to the other forms of dementia such as Alzheimer's disease, where it was more common for women to be diagnosed.
- On average, the number of contacts before a diagnosis were 2, and following diagnosis, 1
- Interventions following diagnosis were explored. A limitation of the data was noted, in that information giving concerning the diagnosis was not explicitly recorded in the database, and planning for the future was only recorded on a small number of occasions. It is likely that completing the database retrospectively through case notes may well not have identified the full range of interventions offered. The following interventions were recorded:
  - Direct Interventions were most commonly Occupational Therapy, Psychology, ACHI prescribing and monitoring, Psycho-education, and memory strategies
  - Information and Advice was most commonly concerning health and well being, followed by information sheets from the Alzheimer's Society
  - Referrals to other agencies was most commonly to the Dementia Advisers followed by referrals to telecare and other third sector agencies
  - Referrals to Admiral Nursing have started to increase
  - Referrals to Dementia Advisers occurred for 96 of the referrals, most commonly in the areas covered by the demonstrator site
- For those diagnosed with dementia, the most common intervention was referral on to others, where as for those with MCI it was Information and Advice. For those not diagnosed with dementia, Information and Advice was the main category
- 17 people left the service immediately following feedback.
- 81.4% of people (n140) were discharged back to primary care
- 16.3% were discharged to their local CMHT (n28)

### **Younger People with Dementia**

- 82 referrals were received, Bromsgrove and Redditch were the highest referrers but also had the highest inappropriate referral rate

- 66 of these referrals were from GP's
- 62 referrals were accepted into the service (19 rejected, did not meet EIDS criteria, 1 declined). Those that were not accepted were referred back to CMHT or primary care. Most rejected referrals were in the first few months of operation of the service
- 13 (21%) chose not to continue after first visit, 79% chose to continue with assessment.
- 53% of those referred were aged between 60 and 64
- Over half of referrals were female which is not consistent with gender differences in dementia at a younger age
- No referrals were received from Black and Minority Ethnic communities despite prevalence being greater at a younger age
- Other demographic characteristics did not differ from usual patterns
- The time spent at different points in the pathway was identified as follows:
  - The average time taken to progress from acceptance of referral to first visit was almost 5 weeks, although the most commonly occurring time spans were 2 to 3 or 4 to 5 weeks. The range was from less than a week, to 14 weeks. 42 (75%) were seen within 6 weeks of date of acceptance of referral
  - The average time from first visit to assessment was almost 4 weeks, and the most commonly occurring time span was either 3 to 4 or 6 to 7 weeks. The range was from under a week between first visit and assessment to just over 10 weeks. 86.8% commenced assessment within 7 weeks.
  - For the time from assessment to diagnosis, the average waiting time was just under 6 weeks, with the most commonly occurring time being 0 to 1 week. The range was from under a week, to just over 33 weeks. 21 referrals (72%) were seen for diagnostic feedback within 8 weeks.
  - For the time from diagnosis to discharge, which incorporates interventions, the average time was almost 6 weeks, with the most commonly occurring frequency of 1 to 2 weeks following diagnosis. The range suggests that whilst some people left the service soon after diagnosis some experienced a longer period of intervention, lasting up to 6 months. 17 referrals (85%) were discharged within 4 weeks of diagnostic feedback
- 12 of the 29 people who have progressed to diagnosis were given a diagnosis of dementia. A further 2 had MCI. The range of diagnostic categories reflect that less common forms of dementia are more prevalent at a younger age
- The average number of contacts prior to diagnosis was 2; the range was 2 to 13.
- The average number of contacts following diagnosis was 1, the range was 1 to 13
- In regard to interventions there was a slight difference in direct interventions from all referrals:
  - Direct Interventions were most commonly Psychology followed by Occupational Therapist

- Information and advice as with all referrals was most commonly health and well being
- Referrals on to other services was most commonly for dementia advisers and telecare

### **Summary**

#### **1. All people with dementia have access to a pathway of care that delivers:**

- **A rapid and competent specialist assessment**
- **A sensitively communicated diagnosis to the person with dementia and their family carers**
- **Immediate treatment, care and support following the diagnosis**

People in receipt of the service identify high levels of satisfaction with the overall process and support they have received. Particular reference has been made to the person centredness of staff and their willingness to listen and enable choices to be made concerning the process for the person experiencing difficulties and their family members/ supporters. While no concerns were raised by those people commenting on the service, the time between appointments appears to be quite significant for some and provides some challenge concerning the ability of the service to achieve the outcome of a rapid assessment, particularly in light of the recent commissioning guidance.

#### **2. People with dementia and their carers to be provided with good quality information on the illness and the services available both at diagnosis and throughout the course of the illness**

The level and nature of information received appeared to be acceptable to those in receipt of the service. Many positive statements were made concerning the level of information given at each point in the journey through the service. The database has not captured the amount of information given at diagnosis and feedback; this does need to be rectified for future evaluation purposes, to accurately reflect team practice.

#### **3. Greatly improved user choice**

395 (86.6%) of all people who were referred and 79.03% of younger people chose to continue with assessment following the first visit. A number of people chose to decline assessment and diagnosis following first visit, both when exploring all referrals (13.2%) and the subset of younger people with dementia (21%). These figures suggest that people were able to make a choice about whether they were ready to receive an assessment. This is clearly positive; however it is important to record reasons for declining the service to understand this further.

#### **4. Giving people with dementia the opportunity to make decisions about their care before their mental capacity is impaired**

The number of people recorded as having considered the future or engaging in advance planning was small (n.32) however a limitation of the database is likely to have contributed to this, in that it was completed retrospectively through examination of case notes. A more accurate picture is likely to be achieved through live completion of the database in future.

#### **5. The provision of a comprehensive and accessible service, focusing on intervention at an early stage**

Although some of those interviewed had difficulties initially with gaining a GP referral for assessment, the majority of respondents indicated they found the service to be accessible and supportive of their needs. This was particularly evident in regard to their comments concerning the receptiveness and person centredness of staff throughout the process; in the range of issues that they felt were addressed by the team following their diagnosis and finally in their belief that the staff would be available to them should they have any further questions or concerns about their situation.

The experience of those using the service suggests that interventions offered are acceptable, of value and timely. Data concerning service use highlights the range of interventions, including direct support from within EIDS, information and advice and referral on to other agencies particularly at discharge. It is difficult to assess whether this outcome is being fully addressed at this stage, as it is recognised that with the volume of referrals received early in the team's inception, when they were not at full staffing capacity, the development of interventions has been delayed. Thus a full picture of the interventions delivered is unlikely to be possible at this stage.

#### **6. Significant engagement with primary care and others to**

- **Raise awareness of the value of early intervention**
- **Stimulate referrals**
- **Reduce negative attitudes to referral**

Referrals have been received at a higher than expected rate for the first year of operation. The majority of these referrals have come from within primary care. However although not recorded on the database, a proportion of these referrals have come to the service via CMHT's. It is therefore difficult to assess whether awareness has increased in Primary Care as a direct result of the work of EIDS. Inclusion of where the referral came from, as well as who the person was referred by within the database would assist in developing a clearer understanding of the extent to which this outcome is being achieved.

#### **7. Achievement of a high appropriate referral rate**

The service has received a high number of referrals in the first year, significantly higher than was initially expected. Although a proportion of these referrals were inappropriate during

the first few months of operation, the number of these has reduced over time, with the exception of the last couple of months where inappropriate referrals increased. However this appears to be associated with a change in referral processes.

#### **8. Achievement of a high acceptability rate with clients**

Data achieved from both the qualitative interviews and satisfaction questionnaire indicate that those receiving the service were overwhelmingly satisfied with the service. In particular the support and sensitivity with which their needs were addressed was valued by participants

#### **9. An increase in the overall number of new cases of dementia seen**

Comparisons with previous referral data to CMHT's is needed to address this outcome

#### **10. Successful engagement with minority groups**

Missing data precludes a full analysis of accessibility and engagement with minority groups. The data that has been recorded indicates that referrals for people from Black and Minority Ethnic groups are low in comparison to population prevalence figures for Worcestershire and nationally across all age ranges. Further work needs to be carried out in engaging with minority ethnic groups and in ensuring that the database is accurately maintained in this regard.

#### **11. An improvement in the quality of life for users and an improvement in the quality of life for family members/carers**

As indicated in the summary of the interviews with people experiencing difficulties and their family members, the service is viewed as improving quality of life, through offering choice; enabling people to find ways of living well with dementia individually and in a relational context; improving self confidence and self esteem. However for various reasons, this small group of participants cannot be seen as representative of the whole. Thus further evaluation, including before and after measures concerning well being and quality of life would be an important next step.

The data achieved for this evaluation has some limitations, which influence the extent to which the work of the team can be effectively measured against the outcomes identified. These include that:

- a) It was not possible to achieve a sample of participants for the qualitative study that reflected the range of people using the service and the different points in the pathway. Further evaluation of the experience of people using the service will need to address these issues
- b) The database was completed using a retrospective exploration of service use through case note analysis. This held a number of limitations including difficulties in

addressing missing data. The database is now being populated as referrals progress through the pathway which should address these limitations

- c) The database was not constructed to record the information giving concerning the diagnosis and the future, including advanced care planning. Thus the work of the team is not adequately represented in this regard. The database will be amended to address this omission.

Future evaluation processes will need to be designed to address these limitations.