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Adults with Learning Disabilities Presenting with Dementia

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EXECUTIVE SUMMARY

Background

As life expectancy improves, increased numbers of people with learning disabilities are suffering from dementia. Supporting someone with a dual diagnosis of learning disability and dementia presents unique challenges to both those responsible for delivering effective services and carers. In response to these challenges Gwent Healthcare NHS Trust developed a Dementia Care Pathway in 2005. Its aims were:

- To ensure early and appropriate diagnosis
- To provide a co-ordinated approach to assessment and intervention
- To develop intervention plans that will support both client and carers
- To provide a process for monitoring the person over time
- To support carers, clients and professionals via the provision of information and training

Research Questions

The study sought to address the following questions:

- What is the impact of training via the dementia care pathway on staff knowledge, confidence and competence in responding to dementia in people with learning disabilities?
- What are the experiences of families/carers of people living with learning disability and dementia?
- What are the views of families/carers on services received and care provided?
- How are the key elements of the Dementia Care Pathway experienced by families/carers?
- How can the Dementia Care Pathway best be utilised in order to meet the care priorities of families/carers living and or working with persons with learning disabilities and dementia?

Methods

A two phase study was carried out producing a combination of quantitative and qualitative data. The first phase involved a survey of staff attending Dementia Care Pathway training at three time points. The second phase comprised semi-structured interviews with paid care staff and family carers who care for someone with a learning disability and dementia.

Key Findings

The stated aims of the Dementia Care Pathway are largely being met. Staff are appreciative of training in the pathway and carers are largely positive about the services they receive. However at the time of participation few people had experienced pathway review meetings and therefore it was difficult to assess longer term benefits for the individual. In addition, a lack of clarity sometimes exists in the minds of carers on what activities specifically relate to the pathway.

Caring for someone with a learning disability pre and post dementia seems to change the experience and present some new challenges. A need to be kept informed, to receive flexible services and to have their views listened to were common themes in the carers' accounts.

Conclusions

In order for the potential of the pathway to be further maximised attention should be paid to increasing the level of information given to carers, widening contributions to pathway review meetings and educating carers on the diverse range of interventions possible through the pathway.

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Introduction

The longevity of people with learning disabilities has risen faster than that of the general population, and the number of people with Down syndrome is expected to increase by 75% between the years 1990 and 2010 (Steffelaar & Evanhuis, 1989). In addition to the sometimes multiple health problems related to their disability, people with learning disabilities are now increasingly likely to suffer age-related diseases including various forms of dementia (Prasher, 2005). Dementia has been defined as:

“A syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of higher quarter functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement”.

(World Health Organisation, 1992)

There has been a scientifically accepted association between Down syndrome and Alzheimer's type dementia (ATD) since 1876 (Prasher, 2005). Prevalence rates for dementia in people with Down syndrome in the UK are:

2% of people aged between 30-39 years

9.4% of people between 40-49 years

36.1% of people between 50-59 years

54.5% of people between 60-69 years

(Thompson, 2002)

People with Down syndrome are not alone in their high incidence of dementia. People with learning disabilities, but without Down syndrome, have been found to be more likely to develop dementia than expected in those aged over 65 years (National Institute for Health and Clinical Excellence (NICE), 2006). Achieving accurate statistics through analysis of empirical evidence is problematic. Some publications refer only to the development of Alzheimer's disease (Janicki, et al, 1996; McKenzie, et al, 2000) and others only to the development of dementia in general (Davies, et al, 2002; McCallion, et al, 2005; Watchman, 2003; Wilkinson & Janicki, 2001). In addition, some authors refer only to the client group with Down syndrome (McKenzie, et al, 2000; Watchman, 2003) and others only to the client group with learning disabilities in general (Davies, et al, 2002; Janicki, et al, 1996; McCallion, et al, 2005; Wilkinson & Janicki, 2001). Despite these problems, there is little doubt about the increase in the number of older people with learning disabilities and dementia.

The diagnosis and management of dementia in this population pose significant new challenges, not just for those experiencing the disease, but also for their carers, be they family or professionals and for both health and social services. In response to these challenges Gwent Healthcare NHS Trust developed a Dementia Care Pathway in 2005. Its aims were:

- To ensure early and appropriate diagnosis
- To provide a co-ordinated approach to assessment and intervention
- To develop intervention plans that will support both client and carers
- To provide a process for monitoring the person over time
- To support carers, clients and professionals via information and training

This research was commissioned to evaluate the impact of the Dementia Care Pathway. The project was managed by a research team consisting of clinicians from Gwent Healthcare NHS Trust, Dr Chris O'Connor, Consultant Clinical Psychologist, Dr Clare Trudgeon, Clinical Psychologist and researchers from the Unit for Development in Intellectual Disabilities (UDID) which is part of the Faculty of Health, Sport and Science at the University of Glamorgan. UDID specialises in integrating research, practice and educational initiatives that focus on people with learning disabilities. The researchers working on this study all had a particular interest and expertise in the area of dementia and people with learning disabilities. The Chief Investigator was Mr Robert Jenkins, Head of the Learning Disability Division and the research team from UDID comprised Dr Rachel Davies, Ms Iliana Sardi and Dr Penny Llewellyn. In addition a statistician, Dr Debbie Keeling, undertook the analysis of quantitative data.

The research took place in two distinct stages. Following the introduction of the Dementia Care Pathway, support staff were invited to attend a series of one day training events on dementia and people with learning disabilities, the pathway and their specific role in its implementation. Stage one of the research, using a quantitative methodology, sought to evaluate the training by answering the question:

What is the impact of training via the dementia care pathway on staff knowledge, confidence and competence in responding to dementia in people with learning disabilities?

The aim of stage two was to seek the views and experiences of carers of people with learning disabilities regarding the Dementia Care Pathway. This stage of the research used a qualitative methodology aimed at answering the following questions:

- 1) What are the experiences of families/carers of people living with learning disability and dementia?
- 2) What are the views of families/carers on services received and care provided?
- 3) How are the key elements of the Dementia Care Pathway experienced by families/carers?
- 4) How can the Dementia Care Pathway best be utilised in order to meet the care priorities of families/carers living and or working with persons with learning disabilities and dementia.

This report will consider the two stages of research separately, before reaching some general conclusions.

Stage 1 - Training

Context

One of the main challenges facing professionals and carers of people with learning disabilities comes in accurately diagnosing dementia at the earliest opportunity. Training of support staff in what are potential indicators of dementia and how to access appropriate services has thus been found to be important if an early and reliable diagnosis is to be made (Watchman, 2003). Davies et al (2002) recommend that tailored training should be offered to staff members in regard to diagnosis, interventions, challenging behaviour and increasing dependency. They encourage the promotion of a multi-agency, multidisciplinary approach of skills and expertise. Accordingly, after the introduction of the Gwent Dementia Care Pathway for people with learning disabilities in 2005, support staff working with people with learning disabilities were invited to attend a series of one day training events on dementia and people with learning disabilities. The training aimed to raise their awareness of dementia in the population of people with learning disabilities and to demonstrate how the Dementia Care Pathway could impact on the care of such people if they developed dementia.

Sample

105 staff members received training. All attendees completed two questionnaires, A (at the start of the day) and B (at the end of the day) which were distributed at the training event. Six months after the training day, questionnaire C was posted to participants and a follow-up letter was later sent in an effort to improve response rates. Twenty seven percent (n=28) of the completed C questionnaires were returned.

At the commencement of the training, those attending were asked to describe their working role. Over 90% of support staff described themselves as either a residential worker, day

service worker, respite worker or social worker. Reflecting the national average for health and social care staff, 80% of staff receiving training were female. Length of service was similarly characteristic of countrywide trends with more than 40% of staff working for over ten years in learning disability services. Seventy nine percent of attendees currently work with at least one person with a learning disability and dementia (21% stated they did not currently work with someone with a learning disability and dementia). Sample distribution by location and age is shown in Tables 1 and 2.

Place of work (Borough)	Completed Questionnaires A/B	Completed Questionnaire C
Caerphilly	3%	0%
Torfaen	19%	25%
Monmouthshire	33%	46%
Blaenau Gwent	32%	29%
Newport	13%	0%

Table 1: Sample distribution by location

Age	A/B	C
Under 25	13%	12%
26-35	16%	12%
36-45	30%	28%
46-55	24%	24%
55+	17%	24%

Table 2: Sample distribution by age

Data Collection

A questionnaire (appendix 1) was distributed to staff at the beginning and end of the training day. Questions covered basic knowledge about people with learning disabilities and dementia, specific knowledge on recognition of dementia, specific knowledge on interventions that can prove helpful, levels of confidence in working with clients who have dementia and perceptions of competence in working in this area. In addition, a six month post-training follow-up was undertaken to assess whether improvements in knowledge, competence and confidence had been maintained and to assess the impact of the training on the working practices of staff (appendix 1).

Data Analysis

Data was entered into SPSS (version 14) for the purposes of quantitative analysis. A range of descriptive statistics, correlations and tests of significance were conducted as appropriate. The questionnaire contained a small number of qualitative questions from which common themes were identified.

Results – Stage 1

As previously described, stage 1 of the research evaluated the training provided to support staff through the Dementia Care Pathway by comparing their knowledge prior to training with their knowledge at the end of the training day. A further evaluation took place six months after training to assess whether staff had retained any increased knowledge. Results of this evaluation are provided here.

Knowledge

Questions in this section were divided into three categories: general knowledge about people with learning disabilities and dementia, recognition knowledge and intervention knowledge. General knowledge was important given the myths and confusion that surround the nature of dementia. Recognition knowledge was considered separately due to the important role direct care staff have in noticing and responding to potential indicators of dementia. The category of intervention knowledge was developed so that staff could consider potential activities that can be used in supporting someone with a learning disability and dementia.

General knowledge

Table 3 shows the distribution of total general knowledge scores (including mean and standard deviation). These were calculated at each time point, i.e. pre-training, post-training and at 6 month follow up.

Percentage of Questions Answered Correctly	General Knowledge (baseline)	General Knowledge (post-training)	General Knowledge (6-month follow up)
0-10%	0%	0%	0%
11-20%	3%	0%	0%
21-30%	5%	0%	4%
31-40%	24%	0%	4%
41-50%	25%	0%	4%
51-60%	15%	0%	11%
61-70%	24%	11%	23%
71-80%	2%	12%	15%
81-90%	1%	20%	11%
91-100%	1%	57%	27%
Mean	49%	88%	73%
(std dev)	(15%)	(11%)	(20%)

Table 3: Total general knowledge scores at each time point

The figures clearly illustrate a trend towards an improvement in general knowledge from a baseline average of 49% correct to a post-training average of 88% correct (a significant difference $t=-23.664$, $p<0.0001$). The average score was 73% at 6-month follow-up; for those people who completed the 6-month follow-up this was significantly different from the post-training score ($t=5.017$, $p<0.0001$) and baseline score ($t=-6.754$, $p<0.0001$).

Individual items that tested general knowledge are analysed in more detail below. Table 4 illustrates knowledge of the correct definition of dementia.

Possible definitions of dementia	Baseline (A)	Post Training (B)	Follow-up (C)
A progressive decline in mental abilities as a result of disease in the brain	78%	100%	92%
An inevitable part of memory decline as a result of the ageing process	21%	0%	8%
An impairment to consciousness	0%	0%	0%
A mental condition that is common in the general population but very rare amongst people with learning disabilities	0%	0%	0%

Table 4: Definitions best describing dementia (bold is correct)

A majority of respondents were able to identify the correct definition of dementia. Importantly, the number of correct answers increased to a maximum 100% following training, with little degradation of learning at time point C. However, it is worth noting that the definition: ‘an inevitable part of memory decline as a result of the ageing process’ was identified as the best definition of dementia by 21% of the respondents pre-training, with some persistence at time point C (8%).

Table 5 shows the responses to the question ‘I believe the conditions listed are types of dementia’.

Which condition is a type of dementia?	Baseline (A)	Post Training (B)	Follow-up (C)
Alzheimer’s	100%	100%	96%
Fronto-temporal	13.5%	93%	65%
Parkinson’s disease	27%	86%	46%
Vascular	10%	97%	62%

Table 5: Knowledge of types of dementia (all correct)

Whilst all respondents were able to recognise Alzheimer’s as a type of dementia, there was little recognition of the other types. There was a significant improvement in recognition immediately following the training. However, there was some degradation of learning at time point C in all categories; although levels were still higher than at pre-training (baseline).

Table 6 illustrates knowledge of the relationship of age to the percentage of people with dementia.

Relationship of age to percentage of people with dementia	Baseline (A)	Post Training (B)	Follow-up (C)
0.1% of people aged 30-59 have dementia	44%	87%	77%
10% of people aged 30-59 have dementia	27%	2%	15%
41% of people aged 70-74 have dementia	38%	3%	15%
4% of people aged 70-74 have dementia	42%	80%	73%
2% of people aged 85-89 have dementia	15%	0%	4%
22% of people aged 85-89 have dementia	60%	94%	81%

Table 6: Relationship between age and prevalence of dementia (bold are correct)

At baseline, approximately 50% of the respondents were able to correctly identify the percentage of people with dementia according to age. There was a significant increase in the number who answered this question correctly immediately post-training with some degradation at time point C.

Table 7 shows the answers to the question ‘What is the extent of dementia within the learning disabled population of those over 65 years?’

What is the extent of dementia in the learning disabled population over 65 years old?	Baseline (A)	Post Training (B)	Follow-up (C)
0.1-0.2%	1%	0%	0%
1-2%	9.5%	0%	4%
10-12%	50.5%	11%	19%
22%	31%	89%	77%

Table 7: Dementia in learning disability population over the age of 65 (bold is correct)

At baseline only 31% of respondents were able to correctly identify that 22% of those aged over 65 years in the learning disabled population had dementia. 50.5% assumed that this percentage was much lower (10-12%). The number of correct responses significantly increased immediately post-training.

Table 8 illustrates knowledge of the types of learning disability which are particularly linked to dementia.

Which form of learning disability is linked to dementia?	Baseline (A)	Post Training (B)	Follow-up (C)
Down syndrome	78%	100%	100%
Fragile X	1%	0%	0%
Prader Willi	0%	0%	0%
Klinefelter’s Syndrome	0%	0%	0%

Table 8: What form of learning disability is linked to dementia ? (bold is correct)

The majority of respondents were able to correctly identify that Down Syndrome was the form of learning disability particularly linked to dementia; 100% answering correctly both immediately post-training and at 6 months follow-up. Table 9 shows respondents’ knowledge of the extent of dementia in people with Down syndrome aged 60-69 years.

Extent of dementia at 60-69 years	Baseline (A)	Post Training (B)	Follow-up (C)
5%	16%	0%	8%
24%	34%	21%	23%
54%	49%	79%	69%
100%	1%	0%	0%

Table 9: The extent of dementia in people with Down syndrome aged 60-69 years? (bold is correct)

Whilst at baseline only 49% were able to identify the extent of dementia in people with Down syndrome aged 60-69 years, this greatly improved immediately post-training. However, it should be noted that approximately one fifth of respondents still believed the extent of dementia to be lower than the actual figure both immediately post-training and at 6 month follow-up.

Table 10 shows respondents' understanding of the term 'differential diagnosis'. Whilst the number of respondents identifying the correct definition of 'differential diagnosis' improved immediately post-training, recall was reduced at time point C.

What is the meaning of the term differential diagnosis?	Baseline (A)	Post Training (B)	Follow-up (C)
That some other medical conditions have similar symptoms to dementia	49%	74%	52%
That everyone with dementia has a slightly different diagnosis	39%	23%	32%
That experts disagree on what is the best definition for dementia	2%	0%	0%
That experts disagree on what is the best way of diagnosing dementia	10%	1%	16%

Table 10: Understanding of the term 'differential diagnosis'? (bold is correct)

Table 11 illustrates participants' knowledge of the life stage in which people with Down syndrome may develop dementia. The majority of respondents were able to correctly identify that people with Down syndrome start to develop dementia earlier than the general population.

At what life stage might people with Down syndrome develop dementia?	Baseline (A)	Post Training (B)	Follow-up (C)
People with Down syndrome start to develop dementia earlier than the general population	82%	96%	85%
People with Down syndrome start to develop dementia later than the general population	1%	0%	4%
People with Down syndrome start to develop dementia at the same time as the general population	8.5%	4%	11%
People with Down syndrome are more likely to receive a diagnosis of dementia as their symptoms will be very obvious	8.5%	0%	0%

Table 11: Knowledge of life stage in which people with Down syndrome are most likely to develop dementia (bold is correct)

In conclusion, general knowledge was sometimes patchy; respondents being aware of general issues relating to dementia in the learning disabled population, but not of specific issues. The research demonstrated that training improved this, and also that knowledge of specific issues was generally retained at 6 months follow-up, although there was some (expected) degradation in learning at 6 months. Differences in general knowledge of dementia based on demographic grouping were also tested. No significant differences were found between general knowledge scores with respect to age, gender or, surprisingly, years of work experience.

Recognition Knowledge

Questions were asked to explore respondents' knowledge relating to recognising possible signs and symptoms of dementia in their clients. The total scores (including means and standard deviations) for recognition knowledge were calculated for all three time-points. Table 12 shows the distribution of these scores.

Percentage of Questions Answered Correctly	Recognition Knowledge (Baseline)	Recognition Knowledge (Post-training)	Recognition Knowledge (6-month follow up)
0-10%	0%	0%	0%
11-20%	0%	0%	0%
21-30%	0%	0%	0%
31-40%	4%	0%	0%
41-50%	5%	0%	0%
51-60%	14%	0%	0%
61-70%	27%	1%	15%
71-80%	27%	11%	23%
81-90%	19%	29%	23%
91-100%	4%	59%	39%
Mean (std dev)	71% (16%)	93% (8%)	87% (12%)

Table 12: Total scores for recognition knowledge at three time points

Although recognition knowledge was good at baseline (71%), the total scores indicate that recognition knowledge significantly increased post-training ($t=-12.974$, $p<0.0001$). For those people who completed the 6-month follow-up the average score was 87%, this was significantly different to both the post-training score ($t=3.597$, $p=0.001$) and baseline score ($t=-5.085$, $p<0.0001$).

Individual items are analysed in more detail below. Table 13 illustrates knowledge of early signs and symptoms of dementia:

I believe these could be early signs and symptoms of dementia	Baseline (A)	Post Training (B)	Follow-up (C)
Communication difficulties	70%	99%	96%
Loss of vision	8%	26%	11%
Memory problems	96%	99%	100%
Heart problems	2%	11%	0%
Wandering	82%	96%	93%
Slowness / withdrawn	77%	98%	93%

Table 13: Recognition knowledge of early signs and symptoms of dementia (bold are correct)

The majority of respondents were able to correctly identify early signs and symptoms of dementia in someone with a learning disability. However, it should be noted that post-training 26% of respondents incorrectly identified loss of vision as an early sign of dementia – an increase from 8%. Respondents were asked about possible explanations for challenging behaviour (table 14).

Possible explanations for challenging behaviour	Baseline (A)	Post Training (B)	Post Training (C)
Individual is suffering from increased blood glucose	11%	18%	18%
Individual is frustrated by their inability to communicate their needs	94%	100%	100%
Individual is intentionally un-cooperative with requests made of them	43%	44%	46%
Individual is suffering pain	36%	71%	57%

Table 14: Recognition knowledge of explanations for challenging behaviour (bold are correct)

Only 36% of respondents were aware that ‘individual is suffering pain’ is a valid explanation for challenging behaviour; however, this did increase post-training. Of concern is that, despite training to the contrary, 43%-46% of respondents continued to believe that ‘individual is intentionally un-cooperative with requests made of them’ was an explanation for challenging behaviour.

Responding to the statement ‘I believe that the following conditions have similar symptoms to dementia and could be confused with dementia’, a high percentage of participants recognised that

depression and hearing impairments could be confused with dementia. However, only 28% were aware that thyroid disorders could also be confused with dementia. Awareness did significantly increase post-training. Unfortunately, in comparison to baseline, a higher percentage of individuals at post-training identified cancer and respiratory problems as having similar symptoms to dementia (Table 15).

Which conditions have symptoms which could be confused with dementia?	Baseline (A)	Post Training (B)	Follow-up (C)
Depression	87.5%	100%	100%
Cancer	13.5%	20%	27%
Thyroid disorders	28%	94%	62%
Hearing impairments	68%	88%	85%
Respiratory problems	8%	33%	15%

Table 15: Recognition knowledge of conditions which have symptoms which could be confused with dementia (bold are correct)

Differences in recognition knowledge based on demographic grouping were tested. In general, no significant differences were found between recognition knowledge scores with respect to age, gender or years of work experience. However, there was one exception, a significant difference ($p=0.029$) was found between recognition knowledge scores and age group immediately post-training (but this difference was not evident at baseline). The recognition knowledge means for each age group were examined (Table 16); those in the 56+ age group had a lower average score (although still high at 88%) on recognition knowledge immediately post-training than the other age groups.

	25 and under	26-35	36-45	46-55	56 and over
Baseline mean (std dev)	68% (15.2)	73% (14.2)	72% (17.0)	69% (14.6)	67% (18.5)
Post-training mean (std dev)	94% (8.8)	97% (9.5)	96% (6.3)	94% (6.7)	88% (8.9)
6-month follow up	89% (11.1)	93% (6.4)	93% (9.1)	87% (10.9)	76% (14.5)

Table 16: Mean recognition knowledge by age group at three time points

Whilst this difference was also evident at 6 month follow-up the effect was no longer significant ($p=0.144$).

Intervention Knowledge

This section of the questionnaire aimed to investigate respondents' knowledge of possible interventions which should take place when a client was suspected of having dementia. The total scores for intervention knowledge were calculated. Table 17 shows the distribution of these scores.

Percentage of Questions Answered Correctly	Intervention Knowledge (Baseline)	Intervention Knowledge (Post-training)	Intervention Knowledge (6-month follow up)
0-10%	1%	3%	0%
11-20%	1%	0%	0%
21-30%	4%	1%	0%
31-40%	3%	0%	0%
41-50%	11%	0%	0%
51-60%	22%	3%	15%
61-70%	31%	6%	26%
71-80%	17%	25%	22%
81-90%	11%	59%	37%
91-100%	0%	4%	0%
Mean (std dev)	66% (16%)	83% (17%)	78% (11%)

Table 17: Total scores for intervention knowledge at each of 3 stages.

As before, scores significantly increased immediately following post-training ($t=-8.088$, $p<0.0001$). For those people who completed the 6-month follow-up the average score was 78%, which was significantly different from the post-training score ($t=3.425$, $p=0.002$) and to a lesser extent the baseline score ($t=-2.110$, $p=0.045$).

Respondents were asked about actions that could be taken if there was a suspicion that someone was showing signs of dementia. The most popular suggested action was to inform someone, namely another health professional, of their concerns. Amongst those health professionals mentioned were General Practitioners (the most popular choice by far), managers and colleagues, community nurses, care managers, social workers, psychologists, learning disabilities teams and occupational therapists. The next two most commonly suggested actions were to support and reassure the individual and to monitor and record their behaviour. Contacting the family or carer and structuring a routine were also mentioned.

Respondents were also asked what actions could be taken to support a carer of someone with a learning disability and dementia. The majority felt that the most effective way to support a carer would be to provide emotional support and reassurance. They also felt that providing advice and appropriate information (e.g. contacts for social services, psychologists and other professionals, support groups, related charities, information about dementia and financial advice) would help. Increased respite and day care, as well as training for the carer were also put forward as suggested actions. In addition, a number of respondents felt that regular multi disciplinary meetings to review the support package of the individual could help to support the carer (table 18).

Interventions which may be helpful for someone with learning disabilities and dementia	Baseline (A)	Post Training (B)	Follow-up (C)
Reassure and give emotional support	100%	100%	100%
Social stories	68%	100%	92%
Exercise	76%	96%	100%
Prescribe drugs	87.5%	100%	88%
Avoid set-routines to keep the person mentally alert	21%	15%	4%
Encourage adequate nutrition	88%	96%	100%
Use memory aids	92%	100%	100%
Electro-Convulsive therapy	4%	0%	0%
Validation therapy	20%	96%	70%
Support activity and stimulation	98%	100%	100%
Use visual aids / prompts	97%	100%	100%
Reality orientation	43%	89%	76%

Table 18: What actions could be taken to support someone with learning disabilities and dementia? (Bold are correct)

At baseline, many respondents were able to correctly identify helpful interventions. However, there were a couple of notable exceptions:

- 20% correctly identified 'validation therapy' at baseline; this increased to 96% post-training.
- 43% correctly identified 'reality orientation' at baseline; this increased to 89% post-training.

Of some concern was that 68% incorrectly identified 'social stories' as helpful and that this figure increased to 100% incorrect post-training. A possible explanation for this could be that the term 'social stories' was not correctly understood by respondents and might have been confused with reminiscence work.

Differences in intervention knowledge based on demographic grouping were tested, however, no significant differences were found between intervention knowledge scores with respect to age, gender or years of work experience.

Beliefs, Competence and Confidence

This section of the questionnaire aimed to elicit respondents' views on their own beliefs and confidence when working with a client who had developed, or was thought to be developing, dementia.

Beliefs towards supporting someone with dementia

To what extent people felt they could impact on the situation was evaluated by asking the question 'How much do you think can be done to support a person with a learning disability and dementia?'

How much can be done to support a person with learning disabilities and dementia?	Nothing can be done				Lots can be done
	0	1	2	3	4
Baseline (A)	0%	1%	6%	29%	64%
Post Training (B)	0%	1%	4%	21%	74%
Follow up (C)	0%	0%	0%	25%	75%

Table 19: How much do you think can be done to support a person with a learning disability and dementia?

Encouragingly, the majority of respondents felt that much could be done to support a person with a learning disability and dementia (table 19).

Self perception of knowledge (in recognising and intervening)

Self perception of knowledge in recognising dementia was tested by asking ‘How much do you know about dementia amongst people with learning disabilities?’

How much do you know about dementia in people with learning disabilities?	I know nothing				I know a lot
	0	1	2	3	4
Baseline (A)	19%	30%	41.5%	10%	0%
Post Training (B)	0%	1%	17.5%	63%	19%
Follow up (C)	0%	0%	21%	61%	18%

Table 20: Self assessment of knowledge of dementia

Self assessment of knowledge improved to a high level immediately following training and held up with remarkable consistency after six months (Chi-squared test significant at $p=0.02$) (table 20).

Self perception of confidence

Respondents were also asked to gauge their confidence in recognising signs and symptoms of dementia in someone with learning disabilities. Confidence levels improved to a high level immediately following training and there was a slight increase after six months, which may represent confidence through the application of what was learnt in training into practice (Chi-squared test result highly significant at $p=0.006$) (table 21).

How confident are you in recognising the signs and symptoms of dementia?	Very unconfident				Very confident
	0	1	2	3	4
Baseline (A)	17%	40%	29.5%	13%	1%
Post Training (B)	0%	2%	27%	59%	12%
Follow up (C)	0%	0%	21%	61%	18%

Table 21: Confidence in recognising signs and symptoms of dementia

Confidence relating to intervention knowledge was tested by asking 'How confident would you feel in knowing what to do if you suspected someone with learning disabilities had dementia?'

How confident would you feel in knowing what to do if you suspected someone with learning disabilities had dementia?	Very unconfident				Very confident
	0	1	2	3	4
Baseline (A)	11%	21%	45%	19%	4%
Post Training (B)	0%	1%	14%	57%	28%
Follow up (C)	0%	0%	14%	50%	36%

Table 22: Self assessment of intervention knowledge

Confidence levels improved to a high level immediately following training and held this level well after six months. The Chi-squared test result $p < 0.0001$ shows that there is a significant relationship between confidence in taking action and training received. The slightly lower confidence ratings for action compared to recognition indicate that staff feel more prepared in their recognition role (table 22).

Participants were asked about concerns relating to working with someone with learning disabilities and dementia. The most common baseline concerns regarded lack of knowledge and understanding about individuals with learning disabilities and dementia and how best to care for and support them. There was also some anxiety about being able to distinguish between learning disability and dementia, and about how they might affect each other. However, respondents felt that with more knowledge, appropriate training and the right support they would not worry about the task and would find working with someone with both learning disabilities and dementia very rewarding.

Immediately following training, respondents frequently commented that they felt more confident and had a better understanding (about working with someone with learning disabilities and dementia) due to the knowledge they had gained from the training day. Table 23 illustrates signs of dementia observed in clients by support staff after they had attended the training day.

Forgetfulness	Loss of short term memory
Confusion	wandering
Indecisiveness	Mood / behaviour changes
“not themselves”	introversion
Aggression	No concept of danger
Vagueness	Problem performing basic tasks
Repeating speech / behaviours	anxiety
Lack of comprehension of what is being said	Slow response (not linked to hearing problem)

Table 23: Signs of dementia observed in clients by staff after they had attended the training day

Evaluation of training

Immediately after the training day, respondents were asked to evaluate the training provided through the Dementia Care Pathway. The overall evaluation of the training was positive in terms of relevance and meeting learning needs (tables 24 and 25).

How relevant do you expect this course to be to your work?	Baseline (A)	Post Training (B)
Very relevant	46%	74%
Quite relevant	51%	24%
Not particularly relevant	1%	2%
Not at all relevant	2%	0%

Table 24: Relevance of training to work

To what extent did this course meet your learning needs?	
Totally met my needs	54%
Met most of my needs	43%
Met some of my needs	2%
Did not meet my learning needs	1%

Table 25: Evaluation of training in terms of learning needs

Respondents were also generally satisfied with the content and delivery of the training (tables 26 and 27).

Satisfaction with content of training day	
Totally satisfied	72%
Quite satisfied	28%
Quite dissatisfied	0%
Totally dissatisfied	0%

Table 26: Evaluation of content of training day

Satisfied with delivery of training day	
Totally satisfied	70%
Quite satisfied	29%
Quite dissatisfied	1%
Totally dissatisfied	0%

Table 27: Evaluation of delivery of training

Additional comments on most useful part of the day

Asked to comment on the most useful part of the training, a majority of respondents perceived this to be education received on dementia including the different types, signs and symptoms and how to recognise dementia. The suggested interventions were also seen as very useful. Many respondents commented positively on the exercises used and credited them with helping them to understand and remember the information given during the day. Interaction with other carers was also seen as beneficial as it allowed the sharing of information and experiences.

Additional comments on learning needs

Asked about additional learning needs most respondents requested regular updates and refresher courses on the material covered in the training day. Many also said they would like more in-depth training within this area, whilst others requested additional reading material to gain further information. Some respondents also felt that hearing about other people's experiences, both carers and individuals with learning disabilities and dementia, would be beneficial.

Applying the training in practice

One of the main reasons for carrying out the six month follow up was to assess retention of knowledge and any longer term changes to practice. Questionnaire C contained a question aimed at distinguishing what proportion of staff had identified that a client they were working with may have dementia (table 28). Subsequent questions explored recognition of signs and symptoms (table 29) and courses of action which were taken when dementia was suspected (table 30).

Had questioned whether client had dementia	25% (n=7)
Had not questioned whether client had dementia	75% (n=21)

Table 28: Questioning whether a client had dementia (post training)

Confusion / disorientation	86%
Observed changes in behaviour	43%
Loss of motivation / withdrawal	43%
Change in eating habits	28.5%
Conversation pauses	28.5%
Concerns noticed by colleagues	14%
Mobility problems	14%
Losing / forgetting things	14%
Skills reduction / increased effort needed	14%

Table 29: Post training recognition of signs and symptoms of dementia (n=7)

Action taken when a client was suspected of having dementia	
Reported it	43%
Communicated to LD nurse / doctor	43%
Memory activities used to stimulate	14%
Checks began as per care pathway	14%
Mapping questionnaire showed individual already being assessed	14%
Strategies to orientate e.g. visual handheld timetable	14%

Table 30: Post training actions taken when suspecting a client has dementia (n=7)

All staff who had noticed one or more of the signs / symptoms mentioned above reported taking some form of action. Two staff members still raised issues that have relevance. One suggested that another condition (Parkinson's) limited what could be achieved and felt that if this had not been present more could have been done. The second proposed that:

“Our duty of care, supervision, liaison with staff or concerns raised by family or the client themselves would all have influenced what action was taken”.

Awareness of any improvements to the clients' care as a result of training.

In most cases either no improvements were mentioned or it was felt that it was too early to notice any improvement. However the following were each mentioned on one occasion:

- staff more aware of client's needs
- more professionals involved
- memory aids now being used
- diagnosis and monitoring
- care is planned with an awareness of condition

Summary of stage 1 results

- 100% of training participants completed the assessment at baseline and immediately post-training. Postal returns at 6-month follow up were just under a third of participants. There is some concern that the profile of those choosing to respond at 6 month follow-up may be different from those non-responders. In particular, responders may have recalled more about the training or had worked with people with dementia and therefore were more interested in responding.
- Training had a positive impact on knowledge, confidence and competence levels and in most cases this was well maintained at six month follow-up.
- A review of the average total scores indicated an increase in general knowledge (from 49% to 88%), recognition knowledge (from 71% to 93%) and intervention knowledge (from 66% to 83%) post-training; with maintenance of learning at 6-month follow-up (some expected degradation in learning was indicated).
- Exceptions to maintenance included – lower recollection of Parkinson's as a form of dementia and understanding of differential diagnosis.
- Training was successful in levelling out differences in knowledge across cohorts. Especially for general and intervention knowledge where a significant difference in baseline knowledge was reduced post-training.
- Most staff thought that they worked with only one or two clients with a dual diagnosis of learning disability and dementia.
- High proportions of staff believed that lots could be done to support people with dual diagnosis, and maintained this view at follow-up.
- In relation to helpful interventions: 20% correctly identified 'validation therapy' at baseline and this increased to 96% post-training; 43% correctly identified 'reality orientation' at baseline and this increased to 89% post-training.
- Confusion between interventions with similar names may explain one unexpected results (100% response for the question about whether social stories would be a useful intervention for someone with learning disabilities and dementia). Social stories are NOT an intervention for use with people with dementia (but life story work is). Participants may have come across social stories at a training day on autism and become confused when life story work was covered during the dementia training.
- Self-perceptions of knowledge on dual diagnosis were most commonly rated as 3 out of 4 (with 4 representing 'I know a lot'). This high rating was maintained at follow-up.
- Self-perceptions of confidence in recognising signs and symptoms was most commonly rated 3 out of 4 (with 4 representing 'very confident')

- Self-perceptions of confidence in knowing what action to take if dementia was suspected was most commonly rated 3 out of 4 (with 4 representing 'very confident') and a significant minority gave a rating of 4
- Of those staff members who had suspected a client had dementia the signs and symptoms noted were largely consistent with those covered in the training
- Confidence in recognition of signs and symptoms of dementia is positively correlated with confidence in knowing what to do when dementia is suspected
- When asked about the relevance of the course to their work the most common response of 'quite relevant' shifted to 'very relevant' at the end of the training
- 54% of staff said the training totally met their learning needs. 43% said training met most needs.
- 72% of staff were totally satisfied with the content of the training
- 70% of staff were totally satisfied with the delivery of the training
- Since the training, the majority of staff had not considered that a client they were working with may have dementia. Therefore questions about what staff did when they were concerned were based on a very small sample (n=7)
- Potential indicators of dementia were consistent with those covered in the training
- Actions taken by staff when they had concerns that a client may have dementia were mainly focussed on reporting, which is in line with the Dementia Care Pathway
- Interestingly the Dementia Care Pathway was only mentioned by name by one respondent
- The follow-up period was felt to be too early for staff to notice improvements as a result of referring their clients to the Dementia Care Pathway

Stage 2 – The views and experiences of carers of people with learning disabilities regarding the Dementia Care Pathway.

Background

Supporting for a person with learning disabilities with dementia can become overwhelming for the individual, family and staff members and this is explored in some detail by Hammond & Benedetti (1999). Initially, the first signs of dementia can be hard to distinguish from other behavioural and/or emotional problems, sensory impairments, other physical health difficulties or general age related changes in people with a learning disability. Even after professional help is sought, carers are faced with the challenge of a deteriorating condition, which is unforeseen and difficult to manage. Emotional distress, behaviours that challenge, psychiatric symptoms and a variety of other health problems can make the care of the individual a daily emotional and physical struggle for carers. Fiscal concerns may arise alongside concerns about dealing with the symptoms of dementia and the individual may require 24-hour care at a comparatively early stage. Lack of knowledge and appropriate training can impede the care of the individual, and it is obvious that competent knowledge and adequate experience is needed in order to care for the needs of a person with learning disabilities who develops dementia (Hammond & Benedetti, 1999).

For people with learning disabilities and dementia who live at home, caring can place a significant potential burden on the family. This has been acknowledged, at least theoretically, by the development of scales to assess the burden of care. The impact of care on families has been accepted to some extent by the National Institute for Clinical Excellence (NICE) who advocate that interventions tailored to people with dementia and learning disabilities should extend to the role of the carers and the impact that caring has on their emotional well-being (NICE, 2006). The latest NICE Guidelines emphasise that, despite the potential challenges, people with learning disabilities and those caring for them should be told about their diagnosis of dementia and have access to adequate services of support (NICE, 2006). Care pathways are one way in which adequate support for people with learning disabilities and dementia can be assured in a manner which is both evidence based and well coordinated.

The role of care pathways as a tool in clinical effectiveness

Care pathways constitute a systematic approach to describing and delivering the services and interventions that should shape care and treatment for a particular condition. They can be utilised in the translation of national guidelines into local protocols and clinical practice (Campbell et al,1998). Integrated Care Pathways (ICPs):

“...use the current best evidence gained from systematic reviews, as well as input from multidisciplinary teams, to outline the optimal course of care for all clients who have a specific condition. They plot out for a particular presenting problem ... the optimal sequence and timing of interventions by physicians, nurses, and other professionals. Because Pathways prescribe treatment and care across different care settings ... they help ensure that a co-ordinated, quality service is provided over the full continuum of care”.

(Scottish Government, Effective Interventions Unit, 2003:1)

Even though care pathways have been implemented throughout the UK, there is minimal empirical evidence of their effectiveness. However, there are a number of studies that have attempted to evaluate the effectiveness of care pathways as a tool in clinical practice. These studies provide empirical evidence for some aspects of care pathways (Campbell, et al., 1998; Currie & Harvey, 2000; De Luc, 2000; Huby & Rees, 2005). For example, Currie and Harvey (2000) argue for the importance of commitment of medical staff as a key role in the implementation of care pathways. They also indicate the importance of the educational needs of teams during the development of the clinical pathway.

De Luc (2000) investigated the effectiveness of care pathways in UK in two different clinical settings (a midwifery-led maternity pathway and a breast disease pathway) with the aim of comparing the changes in clinical care, the satisfaction of patients and the views of staff involved in the pathways. The study revealed that effectiveness depends on where the focus is placed. Namely, even though the development of the care pathways in the study did not seem to pose any significant difficulty resulting in the development of multidisciplinary team working, design of clinical documentation and reviewing and updating of clinical practice, the same was not true for the operationalisation of the care pathways. As the author asserts, operationalisation demands a cultural change on behalf of the clinical staff and continuous commitment to quality improvement, a prerequisite that was not wholly adhered to.

Huby and Rees (2005) have studied the effectiveness of integrated care pathways in a community mental health team and in a rapid response team by focusing on the position of staff members in the hierarchy of the organizations. They found that a care pathway can be effectively implemented by management or teams. Interestingly though, when the care pathway is management-driven then teams fail to engage and vice versa. In order for all key stakeholders to engage in the successful implementation of care pathways then middle management that mediates between management and teams is suggested.

It is perhaps ironic that a particular strength of the pathway approach is that it is based on holistic needs being met via a multi-disciplinary team (Benton, 1999). However, it is this need for the commitment from multiple stakeholders that can make successful implementation of care pathways particularly challenging. Campbell et al (1998) suggest the need for more research to further improve their effectiveness.

Integrated Dementia Care Pathways

There is little published research on the impact of dementia care pathways in practice. An exception is McKenzie et al (2000) who developed a multi disciplinary Care Pathway for people with Down syndrome who developed Alzheimer's disease. On evaluation, they found that utilising this required the cooperation of a wide range of professionals including clinical psychologists, psychiatrists, speech and language therapists, dieticians, occupational therapists, physiotherapists, nurses, GPs, social workers, carers and family members, with each contributing their specialist knowledge at a different stage or stages of the Pathway. McKenzie et al emphasise the importance of on-going commitment to the implementation of the Care Pathway by all those involved, cooperation between services and availability of information among service planners and users. In addition the importance of the educational aspects of implementing a care pathway have been emphasised in research to date (Campbell et al. 1998; Currie & Harvey, 2000).

Gwent Dementia Care Pathway

Given the potential increased prevalence of dementia in individuals with a learning disability a multi-agency working group was established within Gwent NHS Healthcare Trust and local Social Services representatives with members from psychology, psychiatry, occupational therapy, nursing and social work with the aim of developing a Dementia Care Pathway to support all service users with learning disabilities diagnosed with dementia or where a query of dementia arises. A map of the Pathway Process was developed (figure 1) and it was decided that the Pathway could be triggered from Down syndrome screening (which was developed alongside the pathway); via direct referral to the team or via an internal referral of a client already known to services where concerns of possible dementia had arisen. The Pathway can be triggered if there is a query of dementia or if the client already has a diagnosis, but would not apply to individuals over 65 years old with no previous contact with Learning Disability services who should be supported by Older Adult services. The overall aim of the Gwent Dementia Care Pathway is to ensure that people with learning disabilities who develop dementia receive early assessment and timely interventions and support and that there should be regular multi agency review meetings under the guidance of a case coordinator. These meetings should enable the sharing of information and provide a forum for meeting the changing needs of the person as the course of deterioration progresses. The specific aims of the pathway are:

- 1) to ensure accurate early diagnosis
- 2) to provide appropriate information for the service user and his/her carers
- 3) to develop an intervention action plan that will support the service user with dementia and his/her carers
- 4) to provide a process for monitoring an individual's needs over time and ensuring that the intervention action plan is changed to meet the individual's needs
- 5) to co-ordinate a multi-disciplinary response and enable effective multi-agency involvement around service users

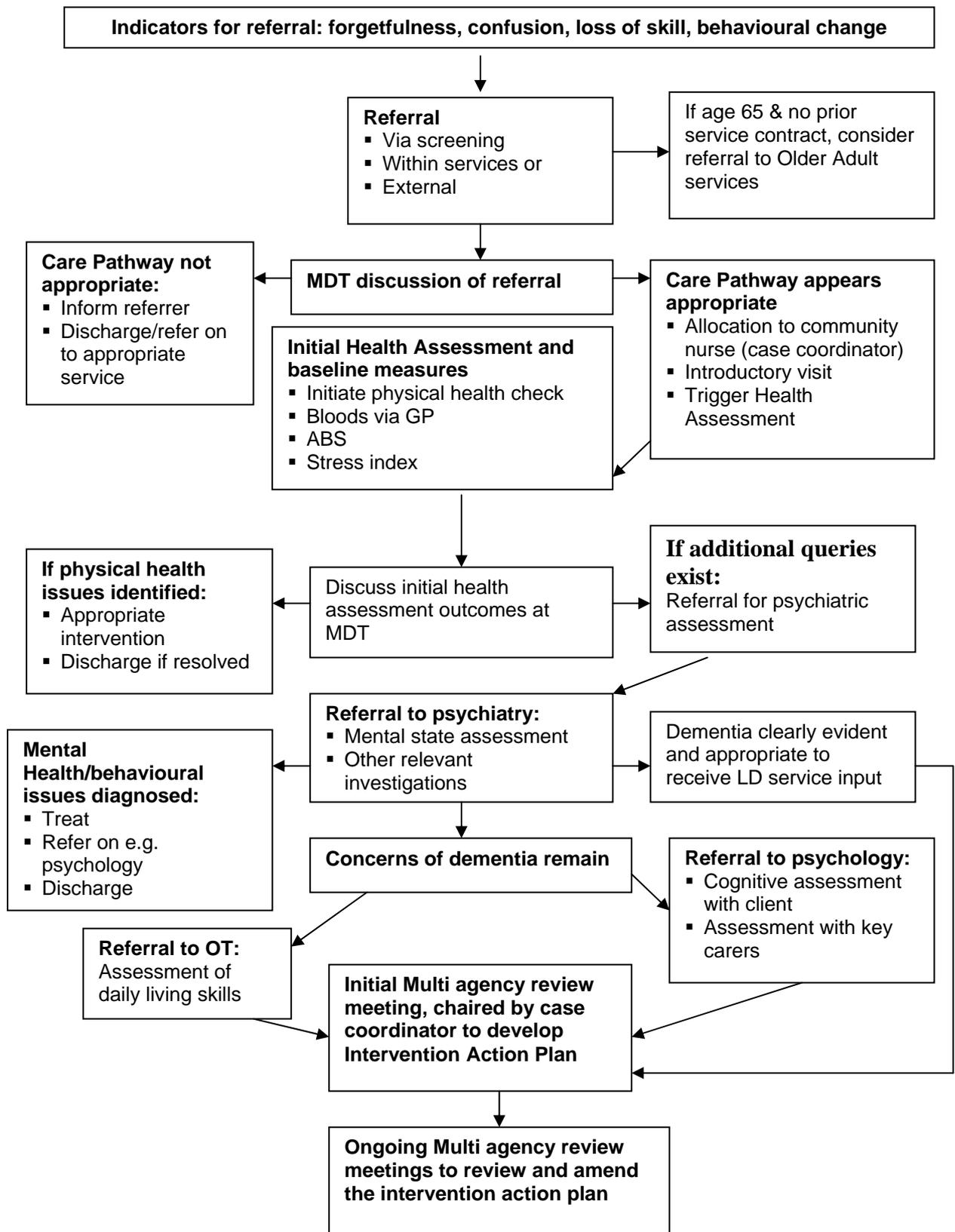


Figure 1: Map of the Care Pathway Process

Aims of stage 2

Although Integrated Care Pathways (ICPs) have been implemented throughout the UK, there is little empirical evidence of their effectiveness. The aim of stage 2 of this study was therefore to evaluate the implementation of the Gwent Dementia Pathway in learning disability from the perspective of primary carers of people with a learning disability who have dementia. The study aimed to answer the following questions:

- 1) What are the experiences of families/carers of people living with learning disability and dementia?
- 2) What are the views of families/carers on services received and care provided?
- 3) How are the key elements of the Dementia Care Pathway experienced by families/carers?
- 4) How can the Dementia Care Pathway best be utilised in order to meet the care priorities of families/carers living and or working with persons with learning disabilities and dementia.

Methods

Qualitative methods are particularly appropriate for exploring experiences and attitudes (Denzin & Lincoln, 1998). They enable the researcher to gain a more detailed understanding of the realities of a participant's experience than can be achieved through collecting quantitative data. Qualitative work also has a tradition of exploratory enquiry enabling new fields of knowledge to be developed via the application of specific methods such as grounded theory.

Grounded Theory

Grounded theory was considered the ideal method for this stage of the study because there is very little previous research on the actual experience of people involved as service users and carers in Integrated Care Pathways. The method differs from other research methodologies in that, rather than aiming to confirm or refute an existing theory i.e. hypothesis testing, it sets out to discover a theory (or theories), which can account for the subject of the research (Glaser 1998).

The process of doing grounded theory requires the researcher to simultaneously collect, code and analyse the data, beginning with the first interview (Hutchinson & Skodol-Wilson, 2001:222). Initially, the researcher breaks up the data by asking questions relevant to the research question i.e. 'What is going on here?', 'What is the situation?', 'How is the person managing the situation?', and coding each sentence and incident. Preliminary ideas are thus generated from the earliest data and

later, in a process of constant comparative analysis, new data is compared with that from earlier interviews and codes from all the accumulated data are condensed into categories. These are then compared with each other to ensure that they are mutually exclusive and cover behavioural variations, making sense of what informants have said. Finally, theoretical constructs weave ‘the fractured data back together again’ (Glaser, 1978:116) conceptualising the relationships among the codes and giving meaning and scope to the resultant theory (Figure 2).

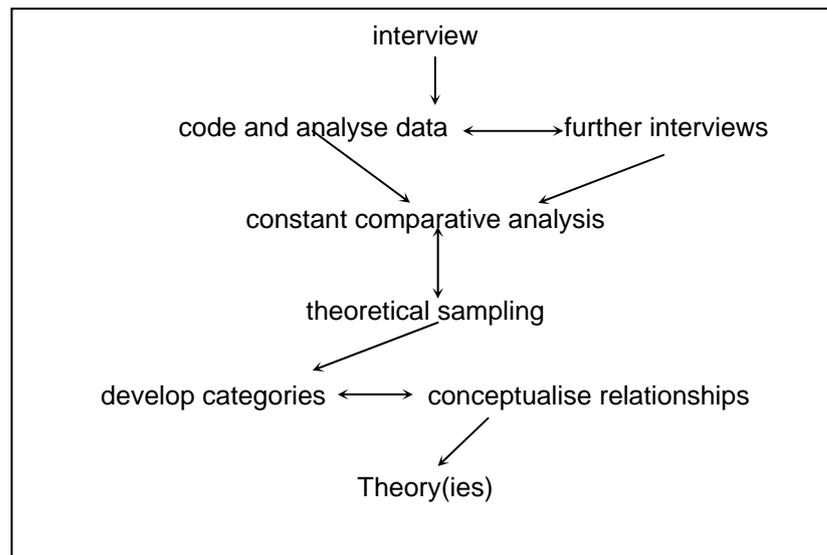


Figure 2: Diagrammatic representation of the Grounded Theory method

Ethical Issues

The main ethical concern for stage 2 related to the consent process and the need to ensure that informed consent was secured before proceeding with data collection. Initially potential participants were visited by a member of the Community Learning Disability Team (CLDT) already known to them. During this meeting the nature of the study was discussed and they were shown the introductory letter and information sheet (Appendix 2, 3 & 4) This gave them the opportunity to consent to an informal meeting with the researcher or to decline further involvement. For those willing to meet the researcher an initial meeting was set up where the project was again explained and the content of the information sheet discussed. Potential participants had the opportunity to ask any questions and were reassured that a decision not to participate would not affect the services that they received in any way.

After not less than two weeks the researcher arranged a second meeting with the potential participants and if they were still interested in proceeding they were asked to complete the consent form (Appendix 5). Participants were told that they would have the right, during the interview itself, to decline to answer questions which they found unduly sensitive. Ethical approval for stage 2 was

obtained from the Local Research Ethics Committee (LREC) and Gwent Healthcare NHS Trust's R&D Committee.

The participants

The participants constituted an opportunistic sample of six clients and their carers, recommended to the researchers because the service users have been referred to the Gwent Dementia Care Pathway. It was initially proposed that the sample should consist of close family members, but there were very few such people taking a day to day caring role and, in the majority of cases, the person with most knowledge of day to day caring for the individual was a paid carer. Ultimately, a flexible approach was taken by the research team concerning the nature of the relationship between carer and client, the important aspect being that the carer had a detailed knowledge of the client and their care needs.

The interviewees for case 1 were a husband and wife caring full time for the service user with dementia under an Adult Placement Scheme, while the interviewee in case 2 was the adoptive mother of the client. Interviewees for cases 3, 4, 5 and 6 were paid support workers, team leaders and/or managers of various supported housing schemes. A seventh case was initially presented to the research team but the carer later declined to take part due to a change in personal circumstances. Only one client with learning disabilities and dementia was present at the interview (case 2).

The interviews

Interviews with cases 1 and 2 were straightforward and took place at the homes of the two service users. The interviewees were full and frank in their opinions regarding caring for a person with learning disabilities and dementia and their experience of the Dementia Care Pathway. Unfortunately, for case 2, the experience of the latter was extremely limited as the client had only just gone onto the Pathway, despite being diagnosed with dementia eleven years previously. Her carer therefore had very little practical knowledge of the Pathway i.e. there had, at the time of the interview, been no review meetings for this client, although there had been a dementia assessment.

The interviewee in case 3 (a support worker) was anxious about being interviewed and expressed a lack of confidence in 'text books and research'. She described her role and experience purely from a 'hands on' perspective. Using one of the tools of grounded theory, i.e. theoretical sampling (Glaser, 1978), the researcher was able to expand on the information given by this interviewee through a subsequent brief telephone interview with the manager involved in this case.

The interviewee in case 4 was a team leader with responsibility for staff issues, training and so on. Although interested to learn what the research was about she was not certain that she could contribute. She was unsure whether or not the client had dementia.

Early indications at the time indicated that the client did not have dementia. The team leader was not aware of any 'Pathway paperwork' existing. Questions related to the impact of dementia, experience of the Pathway, Pathway review meetings etc., were therefore not applicable. The short interview which took place attempted to ascertain changes in the care experience of the client over the years that could possibly reflect some change in health status.

Two interviews took place concerning case 5, the first with the deputy manager of her accommodation (a shared house in a community setting) and the second with a support worker who knew the client well. The interviews took place in the regional office of the national organisation responsible for the house and its residents. The focus in the first interview (with the manager) was to explore her knowledge of the Dementia Care Pathway and in the second (with the support worker) to concentrate on the changing needs of the client and the response of the Pathway to these needs. The manager was confident and knew the client well. She had previously worked as a direct carer herself. Initially the support worker appeared unsure of being interviewed and tape recorded and was anxious about the questions, but relaxed when she began to talk about her work with the client. It was clear that she had close knowledge of the client's changing needs. She was also the only support worker who had been actively involved in Pathway review meetings.

The first interview in case 6 took place at the supported accommodation of the client. The interviewee was a support worker with RNLD status, although she was not employed in this capacity. The home environment was comfortable and the interviewee was very willing to talk about the client and her role as carer, although uncertain when asked about her understanding of the Dementia Care Pathway. Subsequently, in response to questions raised by the analysis of the data from this interview, the manager of the house was interviewed. She was new in post and working both as manager and in a 'hands on' capacity in the house. Having come from a post in England she was able to draw some comparisons between the Pathway and a similar system which she had encountered in her previous position.

Data Analysis

As required by the Grounded Theory method, all interviews were transcribed within a short time of taking place. They were then subjected to computerised qualitative data analysis, using the software package NVivo (version 7), for coding and reduction of the data into categories. The initial codes were developed from the interview transcriptions with the four research questions (see page

32) in mind, and after constant comparative analysis were eventually elevated into two main categories from which theoretical constructs would be conceptualised (table 31).

Role of Dementia Care Pathway	Caring for People with Down Syndrome and Dementia
Carers' awareness/ experience of the Pathway	Participants
Role of the Pathway in diagnosis	Continuity of care
Case Coordinator	Effects of dementia on clients
Review meetings	Challenges in caring for clients who develop dementia
Training	The future
Views of carers on services received and care provided	

Table 31 – Structure of coding scheme

In keeping with Slevin and Sines (1999) approach to enhancing the quality and credibility of qualitative research, the codes were independently developed by two members of the research team and, when compared, were found to have a very high degree of consistency. The researchers also independently agreed that there was clear evidence of two main but associated categories i.e. 'The role of the Dementia Care Pathway' and 'Caring for people with Learning Disability and dementia'. During data analysis some gaps in the data became obvious and theoretical sampling took place in which managers from some of the supported accommodation were interviewed. Further details were also obtained about the providers of the supported accommodation in order to gain a clearer picture of attitudes to and experience of the Dementia Care Pathway.

Results – Stage 2

The results of the second stage of the study will be divided into the two main categories which became apparent at data analysis (figure 2), i.e. 'Caring for people with Learning Disability and dementia' and 'The role of the Dementia Care Pathway'. There are obviously inter-connections between the two and these will be discussed in their appropriate contexts.

Caring for people with learning disabilities and dementia

The participants

Table 32 summarises the background of the participants with learning disabilities in the study. None of the service users were being looked after by their birth families. Case 1 (H) has lived in an Adult Placement Scheme with the same carers for twelve years. She was diagnosed with dementia four years ago when she was 57. Another woman with learning disabilities lives with the family within the scheme and they are joined by a man with learning disabilities at weekends. H's carers noticed the signs and symptoms of dementia four years ago, recognising them from previous experience with an elderly relative, who lived with them previously and had dementia. H also has obsessive compulsive disorder. The main symptom appears to be loss of short term memory, including recognition of familiar people and lack of energy to do things she was previously quite obsessive about, such as tidying. H also wanders at night (but only within the house) and, since the onset of dementia has become incontinent and is inclined to choke when she is eating. She believed she was diagnosed mainly by a clinical psychologist^a after her carers suggested that she might have dementia, but it was a long term process with considerable indecision along the way. The carers were eventually told of the diagnosis by a consultant. H is on several types of medication, risperidone for aggression, prozac for her obsessive compulsive disorder, and thyroxine. She was on drugs for the dementia but suffered severe side effects so the drug was stopped but will be reviewed if necessary in the future. H attends a specialist day centre on a regular daily basis.

^b Conversations with the psychologists clarified that while they are involved in the assessment process they are only one professional who contributes to the multi-disciplinary assessment and diagnosis.

Case	Gender	Living arrangements	Diagnosis by GP and/or consultant	Age	Age at diagnosis
1 (H)	Female	Adult placement (duration 12 years) 1 other female plus 1 male at weekends (both with LDs).	Down syndrome, dementia + obsessive compulsive disorder	61	57
2 (M)	Female	Adoptive family (duration 21 years) 3 adopted siblings all with LDs.	Down syndrome, dementia	32	21
3 (K)	Male	Supported housing (private provider) 2 other tenants	Down syndrome, dementia + depression	56/7	53/54
4 (Y)	Female	Supported housing (private provider) 2 other tenants	Down syndrome, ?dementia, ?menopausal hormonal symptoms	mid 40s	No official diagnosis
5 (B)	Female	Supported housing (national organisation) 1 other tenant	Down syndrome, dementia, cataracts, 'bad legs', agitation	53	52
6 (L)	Female	Supported housing (private provider) 1 other tenant	Down syndrome, dementia, myxodoema, depression	55	53/54

Table 32: Summary of background of participants with learning disabilities

Case 2 (M) was adopted by her present carers twenty one years ago when she was eleven years old, having previously lived in a children's home. She has three adopted siblings, all of whom also have learning disabilities. M was diagnosed eleven years ago aged 21, when it was noticed at college that she had become uncharacteristically forgetful. The diagnosis was suggested by a local consultant, but her adoptive family were unwilling to accept it at such an early age and took her for a consultation to a specialist neuro-surgeon in London. Subsequently, they were sent to a consultant in the Midlands, who diagnosed dementia after examinations and brain scans. The main symptom has been loss of short-term memory which continues to deteriorate. M does not take any medication, even for her epilepsy (her seizures are apparently infrequent). She has structured work experience activities outside the home from Monday to Friday each week.

Cases 1 and 2 have continuity of care in a family type environment. The other four participants live in supported housing schemes with paid staff carers working shifts. Case 3 (K) is '56 or 57'. He shares his supported living accommodation, which is run by a private organisation, with two other men with learning disabilities, one aged 40 and the other aged 'about 54'. It is not clear how or exactly when K was diagnosed with dementia as this had occurred before his main carer (the interviewee) came into post. There has been a rapid decline over the past year. He has short-term memory problems which may be compounded by some difficulties with communication. His carers do 'basically everything' for him in terms of his personal care; he uses a wheelchair most of the time and no longer attends any day services. K takes 'one tablet a day' but the interviewee was uncertain whether this is for dementia or for depression. At the time of the interview he had no structured daily activities either within or outside the home.

Case 4 (Y) is in her mid forties. She shares her supported living accommodation with two other tenants, also with Down syndrome, having previously lived in a hostel for people with learning disabilities. The house has been operational for 3 years. The interviewee (a team leader) had worked with Y in the hostel for seventeen years and has also worked with her since she moved into the house, a total of over twenty years. Y attends a day centre on 4 days each week. She is on medication 'for her thyroid and for her joints, that sort of thing' but the team leader was not aware of an official diagnosis of dementia.

Case 5 (B) is 53 years old. She shares her supported living accommodation, which is run by a large national organisation, with 'her friend F'. B and F had lived together for several years with day time support, but following her diagnosis of dementia, this was increased to 24 hour support 'for her own safety'. The support worker interviewee had been working with B and F in the house for 'seven or eight years' and B was diagnosed with dementia eighteen months before the interview. Staff noticed changes, some of which were at first put down to Bs propensity for teasing staff, but when they realised there was a genuine problem, they contacted the community learning disability team. An assessment took place consisting of questions asked by the community learning disability nurse and a visit to 'a hospital'. Subsequently, staff were told that there was deterioration of the brain cells in one side of Bs brain. B takes one 'aspirin in the morning' and '1 tablet a day to calm her down, which apparently has the side effect of her 'seeming to be tired' all the time. She is not on any medication specifically for dementia. B attends a day centre every day and enjoys some evening activities.

Case 6 (L) is 55 years old. She lives in a bungalow owned by a private company who have several other similar homes in the locality. She shares her home with another woman of similar age who has a learning disability, but not Down syndrome. They have 24 hour support. A previous resident from the home had recently 'moved into nursing care', although the reason for this was not given. L was diagnosed with dementia approximately two years ago after a prolonged period when some physical problem was suspected and she was also treated for depression. She was eventually assessed by a trainee clinical psychologist but as it was difficult to engage L in the assessment process this consisted of information gathering from support staff in the bungalow. The diagnosis was not clear after the first assessment but L deteriorated rapidly allowing a definite diagnosis to be made. It is uncertain how this was communicated to staff. There appears to have been communication by letter which the interviewee said 'explained it to me', but staff were also approached by the community learning disability nurse (who is the case coordinator) who:

“...made herself known to us because we didn’t know that L had or was dementing slowly. You know, we didn’t realise and this nurse said she was part of this team and she would like to come along”

(Support worker)

L is the only one of the six who is on dementia medication. She started taking Aricept some months before the interview and is apparently much improved since. No mention was made of any side effects. She takes thyroxin for her myxodoema and was on Lorazepam for depression (it is not clear whether or not she is still taking this). L relies on staff for all her personal care needs and did not, at the time of the interview, take part in any activities outside her home.

Continuity of care

None of the clients in the study live with their birth families, although both cases 1 and 2 experience continuity of care in family type situations. Case 1 has lived in the same home (an adult placement scheme) with the same carers and the same fellow residents for twelve years. Case 2 was adopted by her family at the age of 11 and is now 32 so has been in the same caring situation for 21 years. The support workers in cases 3 and 6 have been working with their clients for 3 and 2 years respectively and the first interviewee (the deputy manager) in case 5 for ‘quite a while’. The second interviewee in case 5 has been a support worker with the client for ‘7 or 8’ years. The manager in case 6 was new in post at the time of the interview. The interviewee in case 4 had considerable continuity of care with the client, having worked with her for 17 years in a hostel before moving to a smaller home in the community where she had been working with her for 3 years at the time of interview.

Effects of dementia on clients

The effects of dementia on the clients were varied, with deterioration ranging from comparatively swift to very slow. One client (M, case 2) was diagnosed 11 years previously to the interview, at a very young age (21), but is still maintaining her daily work placements. She copes by writing everything down (a programme suggested by the consultant who diagnosed her dementia). Despite this M does have ‘fairy days’ or shorter ‘fairy periods’, where she is unable to remember anything, and there is apparently a continuing deterioration in her short-term memory, which is easily noticeable to her family. Both she and her adoptive mother accept that she may not be able to continue her work placements indefinitely, but are determined that she should go on working for as long as possible as she enjoys her work and it considerably enhances her independence. M has recently undergone some behavioural changes and has started picking at her clothes and rocking.

The client, H, (case 1) also experienced behavioural changes due to dementia, and these affected her attendance at a non specialist day centre. Staff at the centre 'couldn't cope' and 'didn't understand' but some time after diagnosis she was moved to a specialist dementia centre where she appeared to be doing well. Recently staff at the centre have noticed a change in her behaviour which H's carers attribute to the newly extended client base, which now includes clients with Huntingdon's and other mental health problems rather than just dementia. There have been no changes in H's behaviour at home and her carers suggest that H was happier in the smaller setting where the routine and the other service users were known to her.

Depression, apathy and agitation were cited by some interviewees as affecting their clients, and physical deterioration, particularly mobility problems, were common, necessitating adaptations to accommodation in some cases. Until three years ago, K (case 3) was reasonably self sufficient in terms of his personal care although a certain amount of 'nagging' was necessary. He also attended a Day Centre and was involved in an 'allotment project'. There has been a rapid decline in his condition over the past year. He has short-term memory problems, which may be compounded by some difficulties with communication and his carers now do 'basically everything' for him in terms of personal care. K now uses a wheelchair most of the time and no longer attends any day services. Although the support worker mentioned the possibility of K attending a specialist 'dementia' day service, there seemed to be little interest in finding any stimulating activities for him or maintaining his self help skills.

Medication can improve the life of service users with dementia. For some time before her diagnosis, L (case 6) had become increasingly dependent on support staff, and also showed extreme reluctance to leave the house, hanging on to the door frame and crying. Since taking Aricept there has been an improvement in her condition and her reluctance has decreased. L still does not attend any day services but support staff are now encouraging her to leave the house occasionally. Through the Pathway, she has input from an occupational therapist, who has designed and introduced a programme of activities in the home, which staff do with L at regular intervals during the day.

Challenges in caring for clients who develop dementia

Although many problems and difficulties due to the development of dementia in service users were mentioned during the course of the interviews, some of which had obviously caused severe problems to the service user and her/his carers, none of the interviewees were willing to talk specifically about 'challenges' of caring for a person with learning disabilities and dementia. They all implied that they had 'grown into' the extra tasks involved as the dementia developed and that the new tasks and perspectives soon became part of the general routine of caring for that person. In

some cases it had been necessary to adapt client's accommodation and to provide extra staff, and at least one of the interviewees complained that it had taken an inordinate amount of time for these changes to occur.

The future

There was reluctant acceptance among carers working with clients in supported housing schemes and from the adult placement carers that service users with dementia may not be able to remain in their present homes as deterioration due to dementia progresses. Carers in supported housing spoke about clients 'moving on' and 'not being able to stay' in their present accommodation, but did not have a clear idea of options for the future.

"You do [worry] don't you? I mean, I suppose nobody knows how long the stages are do they? It's hard... and when you get to the stage when you can no longer be supported in residential..."

(Support worker)

The support worker working with K had clearly thought that he would have to move on as his physical condition was deteriorating rapidly, but felt the situation had changed since they had been allotted more staff and extra equipment to cope with his condition. She suggested that:

"...he could be here for a good length of time. I mean the family would like him to stay here cos he's so happy here in a way. I mean I know he does have his down days but I mean that's just life. If we all... ...life wouldn't be normal would it?"

(Support worker)

Another service user B (case 5) is, according to both the interviewees, already in need of a bungalow rather than the house she is at present sharing with her friend. It is not clear whether the necessity for a bungalow is caused by B's dementia or whether her 'bad legs', for which she takes regular medication, are more of an issue. Of course, it could be a combination of both these things. The interviewee appeared to expect that B and 'her friend' would move together and have the same support arrangements in the bungalow as they have at present if/when B's condition deteriorates further.

The adult placement carers had looked after a close relative with dementia prior to their involvement with the Adult Placement Scheme and described this as a very difficult time. The relative had eventually moved into residential care as the carers 'couldn't cope', and they accept that the time

might come when they would 'retire' from the Adult Placement Scheme if they find the client's dementia too difficult.

The role of the Dementia Care Pathway

Carers' awareness/experience of the Pathway

"It is essential to ensure that the service user, his or her immediate carers and all the professionals involved in the service user's care are included in the Care Pathway, to ensure ownership of any decisions made and that the agreed action plan is supported by all".

(Gwent Healthcare NHS Trust, 2007)

Despite this aim, knowledge about the Pathway among the interviewees was informal and generally vague. Only one interviewee, a (pseudo) family carer, professed to have received a full explanation of the Pathway at the start of her involvement and to have 'asked lots of questions as well' (case 2). Unfortunately, this participant had only recently gone on to the Pathway and so had very little experience to share with the interviewer.

One deputy manager demonstrated both understanding and familiarity with the procedures of the Pathway, knew when her client had gone on to the Pathway and attended regular review meetings. She remarked that 'lots of professionals' came to the meetings and was also aware of plans for the client, which were sent to her for circulation among the support staff after each review. The support worker interviewee in this case was also knowledgeable about the Pathway review meetings for the client and was the only support worker interviewed who had actually attended these. She spoke of the meetings in very positive terms:

"They [review meetings] are useful. We've had a lot done for [the client] ... since we've been having these meetings". (Support worker)

Despite these positive examples, in many cases there was confusion about the Pathway and whether meetings held to discuss plans for the client were part of the Pathway procedure. One carer provided a typical response to a question about this:

Interviewer: "So you've had at least a couple of review meetings on the Pathway?"

Carer 1 "Yes, well I think it was, yes"

Carer 2 "Well I assume it's on the Pathway, they've never named them as such but..." (Adult placement carer)

Other participants referred to the Pathway as 'it' and 'the thing', appearing to show a lack of formal knowledge about the Pathway.

"I knew he was on the thing, and that is why they brought in those goal plans".

(Support worker)

One support worker was not only vague about the Pathway, but was suspicious of anything she considered academic or research based. She gave the impression that the team caring for the client (K) have little support despite their involvement with the Pathway and that the home (and the client) are therefore quite isolated from mainstream services. This notion seemed validated when, subsequent to this interview, a short telephone interview took place with the manager of K's accommodation, who had been off work for a period. He was vague about the Dementia Care Pathway, saying that he knew little about it. He had received no training and did not appear to know of any paperwork relating to K being on the Pathway. He did speak about meetings with various people involved with K, but was not able to say whether or not these were Pathway review meetings. A conversation with the psychologist involved in this case suggested that this was not a wholly accurate view of the involvement of staff in this home with the pathway. However, a staff member suggested to the research team as being most knowledgeable about K was selected for interview and it was not possible to get a wider picture of staff knowledge about DCP within this home.

Case coordinator

Knowledge about the case coordinator was equally uncertain. All the interviewees were aware of contacts whom they could ring for advice about their clients, or if there was a problem. Some mentioned several people in this context, but did not know whether any of these were the case coordinator. Only two participants expressed certainty about this. One of these had information about, but very limited experience of, the Pathway:

Interviewer: "So in terms of M being on the pathway, they gave you information about it. Did they give you a case coordinator?"

Carer: "Yes she's got a case coordinator, that's L isn't it?"

Client: "Yes"

Interviewer: "And is that a social worker or..."

Carer: "No it's one of the occupational therapists".

(Adoptive parent)

The other had attended Pathway review meetings and knew where to seek help if necessary:

Interviewer: “Who do you turn to if there is a deterioration or if you have concerns?”
Carer “She has got a community nurse, a learning disability nurse and she is involved with the Dementia Care Pathway”
Interviewer “Is she the case coordinator?”
Carer “Yes”. (Support worker)

Role of the Pathway in diagnosis

Only one interviewee was certain that an assessment for dementia had been carried out through the Pathway. The service user in this case had been diagnosed at a very young age (21), but her adoptive parents had been unwilling to accept the diagnosis. They sought advice from several consultants before being given a definite diagnosis and advice on dealing with the situation. A further assessment was carried out through the Pathway, just prior to the interview, but the interviewee was critical of this process. She felt that it was not tailored to the home circumstances of the family or to the intricacies of the client’s familiar daily routine:

“I think the tests that they do are very basic *very basic* I think that’s fine for somebody who’s in probably the second stage of dementia but.... it wasn’t ideal for [the client]”. (Adoptive parent)

Several of the other service users had been diagnosed before the interviewees came into post. Various professionals were mentioned in relation to the diagnosis, including a community psychiatric nurse^c, a clinical psychologist and two consultants. None of these interviewees mentioned the Dementia Care Pathway in connection with the diagnosis.

Review meetings

There was some confusion about review meetings for service users. Four of the interviewees had knowledge about review meetings but they did not always relate such meetings to the Pathway. One carer demonstrated uncertainty when, in the context of discussion about review meetings, he referred to:

“...a programme, there’s about five pages on it and it’s been developed by all the various people”. (Adult placement carer)

^c This was likely to have been a Community Learning Disability Nurse

But then said this had been instituted 'way back, before she had dementia'. The same interviewee remarked that 'they are reviewing it [the programme] every sort of six months', but also described 'contact meetings' and observed that 'we have quite a lot of visits all the time, monitoring and so on'. At least one manager in supported housing was also extremely vague, speaking about meetings he had attended with various people involved with the service user, but not knowing whether or not these were Pathway review meetings.

Only one support worker was certain about review meetings carried out through the Pathway, as she attended these. She explained that they were at present occurring every six to eight weeks due to the rapid deterioration of the service user's condition 'and to see what things need to be put into place and [to discuss] the changes in the person' (support worker, case 5). She was very positive about the nature and frequency of the meetings.

"So I feel yes every six weeks is great because we can all come and get our points across, what we need and what we do and all that".

(Support worker)

This interviewee was the only support worker who had attended review meetings on the Pathway, possibly because meetings were held in the client's home, allowing any staff who felt they had useful information about the client to attend. Other service users in supported housing had been represented at meetings by either the manager of the house or a senior support worker, but not necessarily by their key worker. One manager, who was new in post, and had attended one Pathway review meeting, was now addressing this situation. She had appointed a key worker for the service user:

"...it's one of the staff members who's attended all the network training that we've done regarding dementia... and she'll be attending the next review with me".

(Manager)

This type of intervention could also address the common situation in supported housing in which most 'hands on' workers reported they had not seen any paperwork relating to the Pathway.

Training

Dementia training had been offered to staff in supported housing, but not to carers in 'family' situations, although one of these had been given advice by the diagnosing consultant many years previously. The other, who had previous experience of caring for a relative with dementia, had been given 'lots of literature' and had regular contact with professionals.

Staff attitudes to training have already been discussed in some detail in stage one of this project. They varied from very enthusiastic to distrustful, and there seemed some possibility that opinions were influenced by the ethos of the care provider. One support worker had refused training until a 'staff training day' could be arranged so that 'we would all learn the same thing and there would be no excuse for different interpretations'. In other cases both managers and support workers were enthusiastic about dementia training they had received. One support worker described a training session relating specifically to the client. She explained that this:

"...was based really on what we felt, our concerns and what we would like to know. It was all based on our information". (Support worker)

Asked if this seemed relevant, the support worker was very positive: 'yes it did, it helped quite a lot actually'. However, concerning practical advice on the day to day management of the client, she was less certain:

"That's quite difficult really cos nobody can tell you exactly what to do because every day is different. It comes with experience of caring as well. They can't tell you well 'you have *got* to do this or you have *got* to do that' because you've got to be with [the client] and know her and know her capabilities and what she doesn't like to do. So somebody can't say you've got to do that or do this". (Support worker)

In some cases it appeared that managers, rather than support workers, were attending dementia training and the usefulness of this obviously depended on the manager accurately passing on what (s)he had learned to the 'hands on' support workers. Nonetheless, as stage one of this study demonstrates, training was generally viewed as being constructive and as increasing both knowledge of dementia and of possible behavioural changes in clients experiencing this disease.

Views of carers on services received and care provided.

In general, the interviewees were satisfied with the services being received and the amenities provided for their client although these were not always attributed to the Pathway:

“Well we have a lot of input from all over the place really, we got her community health team and social services and the people that we work for a lot of people come in and give us advice and we have occupational therapy, not so much now, they’ve stopped that now, but we’ve gone through all that, they were trying to help her deal with money you know and all those things, but we’ve gone as far as we can go with those things really. They’ve done all they can and there’s a limit to what you can do”. (Adult placement)

One interviewee, who had minimal experience of the Pathway and had not yet experienced a review meeting, complained that:

“...there’s this lack of communication between all services. They don’t have a central data base that they can draw on. It’s one message passed on from another and if it doesn’t get passed on well that’s it”.

(Adoptive parent)

As this is one of the situations which the Pathway is intending to address, it is possible that she might find an improvement when she and the client have more experience of Pathway review meetings. The manager of one facility, although she was new in post and had very little experience of the Pathway, compared it favourably with the ‘multi disciplinary team’ she had encountered in her previous job in England. She remarked that in her new post, unlike her previous position, she could bring up any issue relevant to the client, however small, and know it would merit consideration at review meetings of the Dementia Care Pathway.

Discussion

The two main categories which emerged from the analysis of the data were: ‘caring for people with learning disabilities who develop dementia’ and ‘the role of the Dementia Care Pathway’. Issues that arose from analysis of these categories will now be discussed and placed in context of wider literature in this area.

For carers of people with learning disabilities the onset of dementia in their clients without doubt adds a different dimension to the caring experience. Family carers often possess the ‘frontline’ observational skills that are necessary for noticing early signs that an individual may have dementia and therefore their understanding of dementia is important (Fray, 2000). For some it may be a step into the unknown or they may have had previous experience of caring for another person with

dementia (as had one interviewee in this study) and so have prior knowledge of the possible future challenges. There were no 'birth families' involved in this study, but one client had been cared for by her adoptive family for 21 years and had experienced dementia for 11 of these. The adoptive mother in this case made light of her situation saying that it was psychologically easier for her than for 'birth' families, as she 'knew what she was letting herself in for' when she adopted her family, and did not have 'guilt feelings' which are sometimes experienced by the natural families of people with learning disabilities. Nonetheless, she had not expected the client to develop dementia at the age of only 21 and had subsequently been extremely forceful in obtaining two 'out of county' diagnoses, one from a consultant in London and a definitive diagnosis from a recognised expert in the Midlands. She acknowledged that she 'fought' for everything and was 'not grateful' for services received by her adopted daughter as she felt that 'there could always be something better'.

Another client had lived in an Adult Placement family for 12 years and had dementia for four of these. This client had received continuity of care in a 'family type' situation, and her carers had previous experience caring for an elderly relative with dementia. As with the adoptive family, Adult Placement carers have full time responsibility for their client, but, unlike the former, they have the option to retire or resign if their responsibilities become too onerous. The Adult Placement Carers in this study mentioned this possibility and although they looked at it only as a last resort, felt that the option to retire decreased the psychological effects of caring for a person with learning disabilities who develops dementia.

While the adoptive family had very little experience of the Pathway, the Adult Placement family were appreciative of having regular meetings and 'plenty of support' in caring for the client, despite being very vague about the constituents of the Dementia Care Pathway, and not differentiating between this and previous support they had experienced. Hammond & Beneddetti (1999) support the role information sharing and practical support play in the ability to give care to a relative in this situation.

The experience of caring for a person with learning disabilities who develops dementia is obviously different for family carers than for paid support staff, even when the latter have worked closely with their clients for a period of years. Where paid staff are the carers, there was an observable difference in the responsibilities of managers and support workers caring for clients who have developed dementia. Managers are responsible for highlighting the need for assessment and diagnosis, but full details of such events appeared to not necessarily be passed to support staff. In some cases there appeared to be a high possibility that paid support staff would not seek out, or have a particular interest in, diagnostic tests or their outcome, feeling these to be of academic interest and their own job to be purely 'hands on' in respect of client support. It is acknowledged that managers may be making efforts to communicate information and that the views of support

workers may not accurately reflect the managers' efforts in this respect. However, the fact that direct care staff lacked knowledge of the pathway is still an important finding.

It appeared that only one client had been invited to a review meeting (she had declined) and few of the interviewees mentioned seeing an action plan. Some were adamant that they had seen no paperwork relating to the Pathway. Those who had attended review meetings rightly saw these as a forum to discuss the client's progress or deterioration and to consider both immediate and future needs, but most were reticent to attribute these meetings directly to the Pathway. In all but one situation involving paid support staff it appeared it was managers that attended review meetings and information emanating from these reviews was not apparently always passed on to support staff. One manager addressed this situation by posting information on a notice board and requested support workers to sign that they had both read and understood it. Despite this, the support worker interviewee involved with that client reported not seeing any information relating to the Pathway.

Even in cases where information had reached support staff, there appeared to be no guarantee that plans decided upon at meetings would be carried out. One interviewee remarked:

“...he did have [goal plans]. He hasn't got them now as much because we couldn't..., no point cos it was just extra work and you got nothing out of it”.
(Support worker)

The same support worker remarked that it had been suggested to her that staff in the house should engage in reminiscence work with the client, but she had been resistant to that because:

“...I mean we did try, but ...I mean my big issue to all that was what if we done something that could open a big can of worms in his past? Not everybody wants to remember everything that went on in the past there are certain things you want to forget...”
(Support worker)

It seems possible that paid staff are influenced by the ethos of care of the providers of the supported living arrangement used by their clients, as the attitudes of the interviewees were very different. Some of the accommodation is owned and run by small private agencies, but one home is run by a large, well known national organisation. This was noticeably the only one in which support staff were able (and apparently encouraged) to attend review meetings and to bring up any concerns they have about the client. Both the manager and support staff in this facility had attended dementia training and also training specific to the needs of their client with dementia. In some accommodation only the manager had attended training and was presumably expected to pass on what (s)he had

learned to support staff. In another, the interviewee revealed possible dissention among the support workers when she explained that they had refused individual training sessions in favour of a 'staff training day' because:

"...otherwise you are just going to have people saying this, this, this and this. It's like any training isn't it? Everybody interprets it different. If we do the training together ...we'll come back and we [should all agree]... so I do think we need to go as a team".

(Support worker)

Probably because it was necessary for all staff to attend this training the support worker reported that:

"...we did have a day booked and then, I don't know what happened to be honest, why it didn't come about so we are still waiting".

(Support worker)

The satisfaction of carers with the Dementia Care Pathway may reflect their position as (pseudo) family or paid staff carers.

Interviewer: "So there's not anything you could say 'Well *this* would improve my job as a carer'?"

Carer: "Not at the moment cos fair play they have got everything possible"

(Support worker)

The primary concern of those carers in 'family' situations was the quality of life for people with learning disabilities and dementia. The adoptive mother expressed concern that her daughter's dementia may prevent her from continuing her present work experience which she enjoys and which enhances her independence. The Adult Placement Carers, although full of praise for the professional input they enjoyed through the Pathway, voiced considerable concern that their client no longer enjoyed her day service due to the remit of the service being broadened. This seems to support the calls made elsewhere for specialist provision that is dedicated to the needs of this client group (Hatzidimitriadou & Milne, 2005).

Paid support staff expressed satisfaction with the support offered even if they lacked clarity on whether this was through the pathway. A question on support available for support workers elicited the following response:

“Oh they are pretty good I’ve got to be honest, his social workers.....so I’d phone her or, like I see a social worker if we had any concerns”

(Support worker)

They were uncritical and even grateful for the services provided and expressed considerable satisfaction with the provision of additional equipment and the appointment of extra staff. These, of course, make the job of supporting clients with deteriorating physical and mental health much easier and appeared to be of paramount importance. Staff in these cases expressed satisfaction with the Pathway, their only complaint being:

“...they need to be working a little bit quicker. I mean I know that they got case loads of people but you know we just need them to be a little bit quicker getting things cos it seems so long winded and you just think ‘just come on’ you know?”

(Support worker)

The Edinburgh Working Group on Dementia Care Practices advises that people with dementia should experience promotion of quality of life supported by a person-centred approach (Janicki & Wilkinson, 2002). However, unlike the carers in family situations, few paid carers expressed concern about the quality of life of their clients. It appeared that none of the clients were receiving psychological input, and the support staff interviewed were unsure about potential of psychological interventions for the service users they work with. In addition in some cases, clients appeared to lack stimulation with few or no services outside the home.

A further theme that emerged through the research was the emotional impact that supporting a person with a learning disability and dementia has on carers. For example one support worker who had worked with her client for over 20 years expressed her sadness at the deterioration caused by her client’s dementia:

“I’m finding it very difficult the way she is at the moment she can’t remember things and like dressing for instance, she gets annoyed because she can’t get it right”.

Watchman (2003) discusses a series of critical issues that arise when people with Down syndrome develop dementia. Traditional types of accommodation are often unable to meet the needs of these people, and as McCallion et al (2005) point out there is no clear guidance as to whether existing environments should be adapted or new ones created in order for services to meet the needs of this population. The concept of ‘ageing in place’ (Watchman 2003; Kerr et al, 2006) is generally accepted to be the ideal situation for people with learning disabilities who develop dementia.

Watchman (2003) discusses the possibility of adapting the environment to enable this, while Kerr et al. (2006) make practical suggestions, including better training and support for direct care staff, the provision of waking night staff and the development of an 'outreach' model of care to enable people to remain in their own homes. Despite these possibilities, when discussing the future of their clients with learning disabilities and dementia, most of the interviewees accepted that there may come a time when the deterioration of their client will make it impossible for them to stay in their present accommodation. None of the interviewees put forward a view as to where their clients might go, and none mentioned the possibility that generic dementia services might be involved in the future care of their clients. In addition, none of the interviewees mentioned the Pathway as a vehicle to assist in possible choices for the future of clients with learning disabilities who develop dementia.

Study Limitations

A full assessment of the long term impact of staff training on practice requires both a long term follow up and a high participation rate. The post training follow up (measure C) was carried out approximately six months after training and although knowledge scores were generally maintained it would have been useful to track this over a longer time period. Unfortunately due to the lower response rate through the postal survey method (n=28) conclusions about the maintenance of knowledge cannot be widely generalised. It is possible that participation in measure C was more likely if people already had a particular interest in the area. In addition a high staff turnover in this area is likely and would mean that some of those attending the training were no longer working in the service at the follow-up point.

The study was carried out during the early days of the implementation of the Dementia Care Pathway. Conversations with professionals who monitor the pathway suggest that some of the problems highlighted in this report have already been addressed and that knowledge and understanding of the pathway has become more widespread as it becomes more established. There was also concern expressed about what it is possible to infer from a small sample (6 case studies in stage 2). Given that most paid staff involved in this study were employed at a support worker level (or equivalent) and were not always the key carer / worker for the client with dementia, detailed knowledge on the pathway and its potential was perhaps an unrealistic expectation. If interviews had been carried out with other professionals involved in the care provision, such as social workers, qualified nurses or psychologists a more informed view of the pathway would have been provided. However what this study has shown is a snapshot of direct care staff and carers' views and experiences at the early stages of involvement in the dementia care pathway.

Conclusion

The aim of the current care pathway is to:

- Ensure appropriate and early diagnosis
- Provide appropriate information for the service user and his/her carers
- Develop an intervention action plan that will support the service user with dementia and his/her carers
- Provide a process for monitoring an individual's needs over time and ensuring that the intervention action plan is changed to meet the individual's needs
- Co-ordinate a multi agency response and enable effective multi-agency involvement around service users

(Gwent Healthcare NHS Trust 2007:3)

In addition the Pathway aims to:

- Provide training at different levels for staff on learning disabilities and dementia
- Develop a format for providing dementia training to staff teams in case workshops

(Gwent Healthcare NHS Trust, 2007.15)

The study demonstrated that, in general, the stated aims of the Dementia Care Pathway are being met. Results of stage one of this research found that the training provided to paid support staff through the Pathway was received enthusiastically and had a positive impact on knowledge, confidence and competence levels in relation to working with clients who have, or may develop, dementia. In most cases this knowledge was well maintained at six month follow-up. Training around dementia in general and more specific to individual service users had been offered to paid support staff but not to carers in 'family' situations. One interviewee (support worker, case 5) in stage two of the study mentioned her satisfaction with training received at a 'case workshop' specific to the client with dementia with whom she was working. There is some evidence that, although staff who had attended training reported it to be 'interesting' and 'very relevant' they still doubted its usefulness in practical day to day situations when caring for their clients.

In stage two, although all the interviewees expressed satisfaction with the Pathway, formal knowledge and awareness of the Dementia Care Pathway did not feature prominently in their lives and there was little recognition about the role of the Pathway in the assessment, diagnosis and care of people with learning disabilities and dementia.

Most interviewees had heard the term 'Pathway' in connection with a service user with dementia, but it was not always credited with the increased support obtained for their clients. Knowledge of the

Pathway was somewhat clearer when clients lived in a 'family' situation, although, even in these circumstances, there seemed to be some confusion. Where paid staff were involved, information was frequently not shared between managers and support staff. Review meetings took place regularly, and, in one case, very frequently, but were seldom attended by support workers working 'hands on' with the service user. Meetings were usually attended by managers and the action plans which evolved from these were sometimes subject to the lack of communication described above. Paid staff were satisfied with provision of equipment which made the job of supporting the client with dementia easier, but seldom implemented other interventions which might improve the quality of life of their clients.

Recommendations

Whilst acknowledging the limitations of this study and developments since the data collection period, there are several recommendations the research team wish to make from the analysis of stages 1 and 2:

1. Carers lack understanding of the DCP, its stages and their role within the pathway. Therefore the DCP needs to be more actively marketed to carers in order to improve understanding, consistency and involvement.
2. Specific information regarding the DCP needs to be communicated more widely to staff and families. For example the potential interventions that could be available via the pathway, the function of the case coordinator and the nature of the pathway review process.
3. Methods to ensure that the closest carers (whether professional or family carers) have an opportunity to feed their thoughts, observations and concerns into DCP review meetings need to be employed.
4. Training around people with learning disabilities who develop dementia should be made available to all carers (including family carers). Client specific training was positively experienced and should be considered for each client on the DCP.
5. Currently the interventions that arise from the pathway are biased towards practical concerns e.g. provision of mobility aids. This balance should be addressed in order that more psychological interventions are included, especially around quality of life.
6. DCP review meetings should be promoted as an opportunity to explore future options and to encourage carers to discuss difficult subjects.
7. Additional research should be conducted into the effectiveness of the pathway as it becomes more established. It is currently too early to say if it is fulfilling its potential.
8. Repeating the baseline assessments of staff knowledge would be useful in determining if the workforce maintains a higher level of knowledge regarding dementia care.

References

- Benton, D. C. (1999) Clinical Effectiveness. In Hamer, S. and Collinson, G. *Achieving evidence based practice: A handbook for practitioners*. London, Baillière Tindall pp. 87-107
- Campbell, H., Hotchkiss, R., Bradshaw, N., Porteus, M. (1998) Integrated care pathways *British Medical Journal* 316: 133-137
- Currie, V. L. and Harvey, G. (2000) The use of care pathways as tools to support the implementation of evidence based practice. *Journal of Interprofessional Care*. 14(4): 311-324
- Davies, M., MacGlade, A. and Bickerstaff, D. (2002) A needs assessment of people in Eastern Health and Social Services Board (Northern Ireland) with intellectual disability and dementia'. *Journal of Learning Disabilities*, 6(1): 23-33.
- De Luc, K. (2000) Care pathways: An evaluation of their effectiveness. *Journal of Advanced Nursing*, 32(2): 485-496
- Denzin, N.K., Lincoln, Y.S. (Eds), (1998) *The Landscape of Qualitative Research: The Theories and Issues*, London: Sage
- Fray, M. T. (2000) *Caring for Kathleen: A sister's story about Down's syndrome and dementia*. Kidderminster, BILD
- Glaser, B. (1978) *Theoretical Sensitivity* Mill Valley C.A., Sociology Press.
- Glaser, B. (1998), *Doing Grounded Theory*, Sociology Press, Mill Valley, CA, .
- Gwent Healthcare NHS Trust (2007) *Care Pathway for Working with Adults with Learning Disabilities Presenting with Dementia*
- Hammond, B. and Benedetti, P. (1999) *Dementia, Aging and Intellectual Disabilities: A handbook*. Philadelphia, Taylor and Francis
- Hatzidimitriadou, E. and Milne, A. (2005) 'Planning ahead Meeting the needs of older people with intellectual disabilities in the United Kingdom'. *Dementia*, 4(3): 341-359.

- Huby, G., and Rees, G. (2005) The effectiveness of quality improvement tools: Joint working in integrated community teams. *International Journal for Quality in Health Care* 17(1): 53-58
- Hutchinson, S. A. and Skodol-Wilson, H. (2001) Grounded Theory: The Method. In P. L. Munhall, C. O. Boyd (Eds) (2001) *Nursing Research: A Qualitative Perspective* (209-243) (3rd Ed.) Boston Jones and Bartlett Publishers.
- Janicki, M. P., Heller, T., Seltzer, G. B. and Hogg, J. (1996) Practice guidelines for the clinical assessment and care management of Alzheimer's disease and other dementias among adults with intellectual disability. *Journal of Intellectual Disability Research*, 40(4): 374-382.
- Janicki, M. P. and Wilkinson, H. (2002) The Edinburgh Principles with accompanying guidelines and recommendations. *Journal of Intellectual Disabilities Research*, 46(3): 279-284.
- Kerr, D., Cunningham, C. and Wilkinson, H. (2006) 'Learning disability and dementia: Are we prepared?' *Journal of Dementia Care*, May/June: 17-19.
- McCallion, P., McCarron, M. and McLoughlin, M. (2005) Overview of dementia issues in Intellectual Disability. *Frontline*, Winter: 14-15.
- McKenzie, K., Paxton, D., Matheson, E., Patrick, S., Hamilton, L., Murray, G. C. (2000) Pathways to success, *Learning Disability Practice*, 3(1): 16-19
- National Institute for Health and Clinical Excellence (NICE) (2006) Dementia: Supporting people with dementia and their carers in health and social care. *Clinical guidelines: CG42 published November 2006*.
- Prasher, V. P. (2005) Alzheimer's disease and dementia in Down syndrome and intellectual disabilities. Oxford: Radcliffe Publishing.
- Scottish Government, Effective Interventions Unit (2003) Effective Interventions Unit Integrated Care Pathway Guide 1: Definitions and Concepts
<http://www.scotland.gov.uk/Publications/2003> accessed April 2008.
- Slevin, E., Sines, D. (1999) Enhancing the truthfulness, consistency and transferability of a qualitative study: utilising a manifold of approaches. *Nurse Researcher* 7(2): 79-97.

Steffelaar JW, Evenhuis HM (1989) Life expectancy, Down syndrome, and dementia *Lancet* / 492-493

Thompson, S. B. N. (2002) Down syndrome and dementia. *Geriatric Medicine*, 32: 47-50.

Watchman, K. (2003) It's your move. *Learning Disability Practice*, 6(8): 14-16.

Wilkinson, H. and Janicki, M. (2001) The Edinburgh Principles. *Sourced at the dementia studies programme*, University of Stirling, Stirling, Scotland.

World Health Organisation (1992) *ICD-10: International Classification of Diseases and Related health problems. (10th rev.)*. Geneva.

Appendix 1 - Questionnaires

Questionnaire for completion immediately prior to (and post) training day

Working with Adults with Learning Disabilities

Presenting with Dementia (A) (B)

This quick questionnaire is designed to assess your knowledge of Adults with Learning Disabilities Presenting with Dementia and your confidence in dealing with this issue. This is being done so that the effectiveness of this training on the care of this client group can be assessed. You will be asked to complete a version of this questionnaire 3 times, at the start of today, at the end of today and in six months time. We would like to have your name and address so that we can contact you in six months to complete the last questionnaire. However, on the questionnaire you will not be asked for your name but instead a code number is allocated to you and will appear on all three versions of your questionnaire. This helps us to see any changes in peoples' answers over time. Only an independent researcher will see your completed questionnaire and it will not be possible to identify anyone from the report she writes.

PLEASE ANSWER ALL QUESTIONS by circling the ONE correct answer unless otherwise indicated

1. How relevant do you expect this course to be to your work?

- a) Very relevant
- b) Quite relevant
- c) Not particularly relevant
- d) Not at all relevant

2. Which of the following best defines dementia?

- a) A progressive decline in mental abilities as a result of disease in the brain
- b) An inevitable part of memory decline as a result of the ageing process
- c) An impairment to consciousness
- d) A mental condition that is common in the general population but very rare amongst people with learning disabilities

3. Which of the following conditions are types of dementia (circle ALL that apply)?

- a) Alzheimer's
- b) Fronto-temporal
- c) Parkinson's disease

d) Vascular

4. Circle all of the following that you think are TRUE

- a) 0.1% of people aged 30-59 have dementia
- b) 10% of people aged 30-59 have dementia
- c) 41% of people aged 70-74 have dementia
- d) 4% of people aged 70-74 have dementia
- e) 2% of people aged 85-89 have dementia
- f) 22% of people aged 85-89 have dementia

5. Circle ALL of the conditions that have similar symptoms to dementia and could be confused with dementia?

- a) Depression
- b) Cancer
- c) Thyroid disorders
- d) Hearing impairments
- e) Respiratory problems

6. As far as you know how much of your current workload involves working with people with learning disabilities AND dementia?

- a) I do not work with anyone who has a learning disability AND dementia
- b) One or two people I work with have a learning disability AND dementia
- c) I regularly work with people who have a learning disability AND dementia
- d) Virtually everyone I work with has a learning disability AND dementia

7. What is the extent of dementia within the learning disabled population of those over 65 years?

- a) 1-2%
- b) 10-12%
- c) 0.1-0.2%
- d) 22%

8. Which form of learning disability is particularly linked to dementia?

- a) Down Syndrome
- b) Fragile X
- c) Prader Willi
- d) Klinefelter's Syndrome

- 9. What is the extent of dementia in people with Down Syndrome aged 60-69 years?**
- a) 5%
 - b) 24%
 - c) 54%
 - d) 100%
- 10. Which of the following could be early signs or symptoms of dementia in someone with a learning disability (Circle ALL that apply)**
- a) Communication difficulties
 - b) Loss of vision
 - c) Memory problems
 - d) Heart problems
 - e) Wandering
 - f) Slowness / withdrawn
- 11. Sometimes people with learning disabilities and dementia present with behaviours that are challenging or difficult to manage. Can you identify ALL of the reasons why these behaviours may occur.**
- a) Individual is suffering from increased blood glucose
 - b) Individual is frustrated by their inability to communicate their needs
 - c) Individual is intentionally un-cooperative with requests made of them
 - d) Individual is suffering pain
- 12. What do you understand by the term 'differential diagnosis'?**
- a) That some other medical conditions have similar symptoms to dementia
 - b) That everyone with dementia has a slightly different diagnosis
 - c) That experts disagree on what is the best definition for dementia
 - d) That experts disagree on what is the best way of diagnosing dementia
- 13. Which one of the following statements is TRUE**
- a) People with Down's Syndrome start to develop dementia earlier than the general population
 - b) People with Down Syndrome start to develop dementia later than the general population
 - c) People with Down Syndrome start to develop dementia at the same time as the general population
 - d) People with Down Syndrome are more likely to receive a diagnosis of dementia as their symptoms will be very obvious

14. How much do you think can be done to support a person with a learning disability and dementia?

Nothing can be done Lots can be done
 0 1 2 3 4

15. Complete the following table indicating which interventions could help someone with learning disabilities and dementia and which would not help (place a tick in relevant box)

	This intervention could be helpful	This intervention would not be helpful	Don't know the answer
Reassure and give emotional support			
Social stories			
Exercise			
Prescribe drugs			
Avoid set-routines to keep the person mentally alert			
Encourage adequate nutrition			
Use memory aids			
Electro-Convulsive therapy			
Changing the environment around the person			
Validation therapy			
Support activity and stimulation			
Use visual aids / prompts			
Reality orientation			

16. Suggest 3 actions you would take if you suspected that someone you care for may be showing signs of dementia

- a).....
.....
- b).....
.....

c).....
.....

17. Can you suggest up to three things you could do to support a carer of someone with a learning disability and dementia?

a).....
.....

b).....
.....

c).....
.....

18. How much would you say you currently know about dementia amongst people with learning disabilities?

I know nothing I know a lot
0 1 2 3 4

19. How confident would you feel in recognising signs and symptoms of dementia in someone with learning disabilities?

Very unconfident Very confident
0 1 2 3 4

20. How confident would you feel in knowing what to do if you suspected someone with learning disabilities had dementia?

Very unconfident Very confident
0 1 2 3 4

21. Can you add anything about how you feel about working with someone with learning disabilities and dementia

.....
.....
.....
.....

The final questions relate to you and your role. The reason we ask these questions is that we want to know more about what different groups get out of training in order that we can improve training in the future.

1. Gender

- a) Male
- b) Female

2. Age range

- a) under 25
- b) 26-35
- c) 36-45
- d) 46-55
- e) over 56

3. How would you describe your job

- a) Day service worker
- b) Residential worker
- c) Family carer
- d) Family aide
- e) ILF worker
- f) Other (state).....

4. How long have you been working with people with learning disabilities?

- a) Less than one year
- b) 1-5 years
- c) 5- 10 years
- d) Over ten years

We would like to thank you for participating in this questionnaire. You will be asked to complete the second part at the end of the training.

Follow up questionnaire 6 months post training ©

Working with Adults with Learning Disabilities
Presenting with Dementia

SECTION A (Circle ONE response for each question in this section)

1. How much would you say you now know about dementia amongst people with learning disabilities?

I know nothing I know a lot
0 1 2 3 4

2. How confident do you now feel in recognising signs and symptoms of dementia in someone with learning disabilities?

Very unconfident Very confident
0 1 2 3 4

3. How confident do you now feel in knowing what to do if you suspected someone with learning disabilities had dementia?

Very unconfident Very confident
0 1 2 3 4

4. What concerns (if any) would have about working with someone who has dementia?

.....
.....
.....

5. What possible signs and symptoms of dementia have you observed in clients since undertaking the training?

.....
.....
.....

- d) A mental condition that is common in the general population but very rare amongst people with learning disabilities

12. Which of the following conditions are types of dementia (circle ALL that apply)?

- a) Alzheimer's
- b) Fronto-temporal
- c) Parkinson's disease
- d) Vascular

13. Circle all of the following that you think are TRUE

- a) 0.1% of people aged 30-59 have dementia
- b) 10% of people aged 30-59 have dementia
- c) 41% of people aged 70-74 have dementia
- d) 4% of people aged 70-74 have dementia
- e) 2% of people aged 85-89 have dementia
- f) 22% of people aged 85-89 have dementia

14. Circle ALL of the conditions that have similar symptoms to dementia and could be confused with dementia?

- a) Depression
- b) Cancer
- c) Thyroid disorders
- d) Hearing impairments
- e) Respiratory problems

15. As far as you know how much of your current workload involves working with people with learning disabilities AND dementia?

- a) I do not work with anyone who has a learning disability AND dementia
- b) One or two people I work with have a learning disability AND dementia
- c) I regularly work with people who have a learning disability AND dementia
- d) Virtually everyone I work with has a learning disability AND dementia

16. What is the extent of dementia within the learning disabled population of those over 65 years?

- a) 1-2%
- b) 10-12%
- c) 0.1-0.2%
- d) 22%

17. Which form of learning disability is particularly linked to dementia?

- a) Down Syndrome
- b) Fragile X
- c) Prader Willi
- d) Klinefelter's Syndrome

18. What is the extent of dementia in people with Down Syndrome aged 60-69 years?

- a) 5%
- b) 24%
- c) 54%
- d) 100%

19. Which of the following could be early signs or symptoms of dementia in someone with a learning disability (Circle ALL that apply)

- a) Communication difficulties
- b) Loss of vision
- c) Memory problems
- d) Heart problems
- e) Wandering
- f) Slowness / withdrawn

20. Sometimes people with learning disabilities and dementia present with behaviours that are challenging or difficult to manage. Can you identify ALL of the reasons why these behaviours may occur.

- a) Individual is suffering from increased blood glucose
- b) Individual is frustrated by their inability to communicate their needs
- c) Individual is intentionally un-cooperative with requests made of them
- d) Individual is suffering pain

21. What do you understand by the term 'differential diagnosis'?

- a) That some other medical conditions have similar symptoms to dementia
- b) That everyone with dementia has a slightly different diagnosis
- c) That experts disagree on what is the best definition for dementia
- d) That experts disagree on what is the best way of diagnosing dementia

22. Which one of the following statements is TRUE

- a) People with Down Syndrome start to develop dementia earlier than the general population
- b) People with Down Syndrome start to develop dementia later than the general population
- c) People with Down Syndrome start to develop dementia at the same time as the general population
- d) People with Down Syndrome are more likely to receive a diagnosis of dementia as their symptoms will be very obvious

23. How much do you think can be done to support a person with a learning disability and dementia?

Nothing can be done Lots can be done
 0 1 2 3 4

24. What do you understand the main purpose of the 'dementia care pathway' is?

.....

25. What do you understand the role of the 'care pathway coordinator to be'?

.....

26. Suggest 3 actions you would take if you suspected that someone you care for may be showing signs of dementia

a).....

 b).....

 c).....

27. Can you suggest up to three things you could do to support a carer of someone with a learning disability and dementia?

- a).....

- b).....

- c).....

28. Complete the following table indicating which interventions could help someone with learning disabilities and dementia and which would not help (place a tick in relevant box)

	This intervention could be helpful	This intervention would not be helpful	Don't know the answer
Reassure and give emotional support			
Social stories			
Exercise			
Prescribe drugs			
Avoid set-routines to keep the person mentally alert			
Encourage adequate nutrition			
Use memory aids			
Electro-Convulsive therapy			
Changing the environment around the person			
Validation therapy			
Support activity and stimulation			
Use visual aids / prompts			
Reality orientation			

29. Have you identified any additional learning needs you have in relation to people with learning disabilities who have dementia

.....
.....
.....

THANK YOU for completing the final part of the questionnaire. Please send it back in the enclosed FREEPOST envelope. Remember your response is anonymous and we will not be able to identify you.

Appendix 2 – Letter of invitation

Date

Dear (insert name)

Research Study – Adults with Learning Disabilities Presenting with Dementia

We are writing to you from the Unit for Development in Intellectual Disabilities (UDID) at the University of Glamorgan. We are researchers who specialise in research about people with learning disabilities.

Gwent Healthcare NHS Trust and the University of Glamorgan are conducting research into the experiences of having both a learning disability and dementia. We are meeting with individuals and their families to find out about the services they receive and the care provided. You are receiving this letter as the Community Learning Disability Team (CLDT) think you may be able to help us with this research.

The enclosed information sheet gives you more details about our research and how you could help us. There is no obligation to do so, however this work is important in adding to what is known about the experiences of individuals and families. Therefore we ask that you take the time to read the information sheet and feel free to ask any questions to a member of the CLDT. Alternatively you can contact myself by telephone on 01443 483155 and I will happily deal with any queries you may have.

Yours sincerely

Mr Robert Jenkins (Chief Investigator)

Appendix 3 – Participant information sheet (carer)

Research Study – Adults with Learning Disabilities Presenting with Dementia



Hello. We are Iliana Sardi and Rachel Davies and we work as researchers at the University of Glamorgan. We are doing research with people with learning disabilities who have dementia and their families.

Why are we doing this research?

Families of people with learning disabilities who have dementia are not very often asked their opinions. But your experiences are important in how services are developed and care is provided. We want to know about your experiences of caring for someone with a learning disability and dementia. We are wanting to do this research because we want to make services better for people with a learning disabilities who have dementia and their carers.

Why are we writing to you?

We don't know who you are yet. This information is being given to you by a member of the Community Learning Disability Team (CLDT). But if you agree one of us would like to come and meet with you and tell you more about the research. You would then have some time to think about whether you want to take part in the research.

What would happen if you agree to take part?

We will come and see you at a time and place to suit you, including in your own home if you prefer. We will ask you some questions about your family member who has learning disabilities and dementia, the care and services they receive and your experiences as a family carer. We will record your answers on a tape recorder. We will then write out what is on the tape and use it to help us to write a report. The tapes will be kept in a locked, secure place.

What about the person with learning disabilities? Will we ask them questions?

We would like to find out what they think about their care and services but realise that they may not want / be able to talk to us. This is something for you to think about as a family or to discuss with the CLDT. Even if your family member can't talk to us we would still like to talk to you.

What about your privacy?

If we ask you a question that seems too private you don't have to answer it. The tape recording will not include your name or anything else that would identify you. If you mention a name or a place on the tape we will not write it down. No one else will know what you say to us not even your nurse, psychologist or social worker. When we have visited several families we will write our report. Anyone reading the report will not be able to tell who we have visited.

What if you don't want to take part or change your mind?

No one has to take part. Not taking part will not affect services you or your family member receives in any way. You will have time to think about taking part and can decide against it at any time.

What to do if you are happy to meet with us to talk about the project more?

Let someone in the CLDT know and they will pass your details onto us. One of us will then call you and we will come and meet with you to discuss the project.

What if you still have some questions?

You can phone our manager Mr Robert Jenkins (01444 583155) or email him at rjenkins@glam.ac.uk . Or you can tell your CLDT that you would like to meet us and one of us will come and see you and answer any questions you may have.

Appendix 4 – Participant information sheet (individual)



ILIANA



RACHEL

Hello. We are ILIANA and RACHEL. We work at the University of Glamorgan.

We are doing some work with people with learning disabilities who have dementia. We want to know about their lives and to find out if things can be made better for them.

We would like to come and talk with you. Only one of us would come.

We would like to come and see you two times. We can come to see you at home or somewhere else you like.

The first time we would tell you more about what we are doing, meet your family carers and get to know you.

The second time we would ask you some questions about your life, the services you use and the care you have. You can tell us what you are happy with and what you are not happy with. You won't have to answer questions you don't want to. If you say you want us to come and then change your mind that is OK. You can change your mind at any time.

Your family carer can be with you or you can talk to us alone.

We will record what you say on a tape recorder. When we get back to the office we will listen to the tape and write down what you say.

After we have visited some other people we will write a big report about what people tell us.

We will not use your name or address in the report.

Talking to us will not affect the services you receive in a bad way.

If you decide you don't want us to come and see you then that is OK.

You can show this letter to your family if you want to. If you have any questions you can:

Telephone your CLDT on.....

Telephone the University on.....

Or write to us at.....

Appendix 5 – Consent form (University of Glamorgan headed paper)

Research Study – Adults with Learning Disabilities Presenting with Dementia

Please tick boxes to say you agree with the following:

I have met with the researcher and been told about the research

I have been given a copy of the information sheet

My questions have been answered

I have had time to think about whether I want to take part.

I know that my name will be not be used in any report

I understand that it is OK if I change my mind and don't want to take part

I understand that my services will not be affected if I don't want to take part

I would like to help with this research

Please sign your name here_____

Print name

Contact Address

Date

