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Learning Disability & Dementia - A Review of Recent Literature.

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ABSTRACT

Introduction

People with learning disabilities are living longer and are therefore increasingly developing age related conditions. Dementia is particularly prevalent amongst people with Down syndrome. The diagnosis and management of dementia in the learning disabled population raises a number of challenges for services.

Methods

A review of 170 articles published between 1996-2006 was undertaken. Data was collected in relation to diagnosis, needs, models of support and service provision.

Results and Discussion

Regular medical and psychological assessments that start early enough is a key recommendation in ensuring early and accurate diagnosis. Services that can be flexible in providing ongoing care is also important with 'ageing in place' widely advocated. Although the needs of this client group span multiple service structures, learning disability services need to be at the heart of service provision. This in turn requires a wider knowledge base amongst staff in learning disability services about the nature of dementia.

Conclusion

While raising interesting idea that regularly arise in the literature this review has been limited by the lack of large scale, longitudinal work in this area. In particular a county wide audit of services is called for as a first step in ensuring good practice in the management of dementia and learning disabilities.

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GLOSSARY OF ABBREVIATIONS

ABS = Adaptive Behaviour Scale

ABDQ = Adaptive Behaviour Dementia Questionnaire

AD = Alzheimer's Disease

ATD = Alzheimer's Type Dementia

CAMCOG = Cambridge Cognitive Examination

CAMDEX = Cambridge Examination for Mental Disorders in Older People

CB = Challenging Behaviour

CLD = Checklist with Symptoms of Dementia

CRT = Cued Recall Test

DFT = Dementia of Frontal Type

DMR = Dementia Questionnaire for Persons with Mental retardation

DMTS = Delayed Match to Sample Test

DS = Down Syndrome

DSDS = Dementia Scale for Down syndrome

DSMSE = Down syndrome Mental State Examination

DTI = Dementia Type Illness

Edinburgh Principles = Seven statements which identify the foundation for the design and support of services to people with LD affected by dementia and their carers (see Janicki & Wilkinson, 2002).

ID = Intellectual Disability

LD = Learning Disability

MEAMS = Middlesex Elderly assessment of Mental State.

MMSE = Mini Mental State Examination

MOSES = Multidimensional Observation Scale for Elderly Subjects

PBC = Personality and Behavioural Changes

PCFT = Prudhoe Cognitive Function Test

PD = Psychiatric disorder

PSS-LD = Present Psychiatric State for PLDs - Psychiatric Assessment Instrument for PLDs

SBIS = Stanford Binet Intelligence Scale

SCS = Sum of Cognitive Scores

SOS = Sum of Social Scores

SRT = Selective Reminding Test

TSI = Test for Severe Impairment

UPDRS = Unified Parkinson's Disease Rating Scale

WISC-R = Weschler Intelligence Scale for Children – Revised

1. INTRODUCTION

The longevity of people with learning disabilities has risen faster than that of the population in general, and the number of people with Down syndrome is expected to increase by 75% between the years 1990 and 2010. In addition to the sometimes multiple pathologies related to their learning disability, these people 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 are several different types and causes of dementia, the most common being:

- Alzheimer's disease in which excess amyloid protein is present in the brain and which may also feature the amyloid precursor protein (APP) gene located on chromosome 21 (Martin, 1998);
- Multi-infarct dementia, which results from the destruction of brain tissue by a series of small strokes; (Martin, 1998)
- Lewy body dementia (LBD) associated with the neuropathological changes seen in Parkinson's disease (Prasher, 2005)
- Fronto-temporal dementia in which there is marked degeneration of the frontal and temporal lobes of the brain (Prasher, 2005).

People with learning disabilities may suffer from any of these forms of dementia and there has been a scientifically accepted association between Down syndrome and Alzheimer's type dementia (ATD) since 1876. 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)*

Several independent research studies have confirmed that most adults with Down syndrome over the age of 40 show pathological changes related to Alzheimer's dementia, but there is frequently a disparity between the presence of Alzheimer's neuropathology and the clinical presentation of the disease in adults with Down syndrome (Zigman *et al.*, 1997)

The signs and symptoms of dementia vary, although almost all affected individuals have the characteristic progressive and severe memory loss. For people with learning disabilities, their underlying personality, the severity of their intellectual disability, general health status, social and cultural background, and the cause of their dementia will contribute to the overall picture (Prasher, 2005). The increase in the number of older people together with the diagnosis and management of dementia in this population, poses significant new challenges, not just for those experiencing the disease, but also for their carers, be their family or paid support staff, and for both health and social services.

1.1 Review questions

This literature review was commissioned to address the following questions:

1. How can we ensure better awareness/detection regarding early diagnosis of dementia and dementia type illnesses in people with learning disabilities?
2. What are the needs of people with learning disabilities who develop dementia type illnesses?
3. What models of support are available to meet such needs?
4. Which service sectors are taking the lead in the development and delivery of services for people with learning disabilities who develop dementia

2. METHODS

2.1 Literature search

Table 1: SEARCH TERMS ON LEARNING DISABILITY
Learning disability
Learning disabilities
Learning difficulty
Learning difficulties
Developmental disability
Developmental disabilities
Intellectual disability
Intellectual disabilities
Mental retardation
Mental handicap
Down syndrome

Table 2: SEARCH TERMS ON DEMENTIA
Dementia
Dementia type illness
Alzheimer's disease
Dementia assessment
Dementia services
Dementia support

The literature search for this study was conducted mainly online, using the databases Psychinfo, Zetoc, Cinahl, Medline, Assia, and BNI. 11 different search terms relating to 'learning disabilities' (table 1) were combined with 6 different search terms relating to 'dementia' (table 2), resulting in 66 combinations.

2.2 Inclusion criteria

The inclusion criteria for the study required papers to have been published in the ten years between January 1996 and December 2006 and to have been written in the English language. Papers were considered relevant only if they focused on at least one of the following:

- The identification and assessment of dementia type illnesses in people with learning disabilities.
- The needs of people with learning disabilities who develop dementia type illnesses
- The models of support which have been proposed and developed to meet such needs
- The priority services taking the lead in the development and delivery of such services

The literature searches resulted in over 500 papers, which were reduced to 200+ after selection/deletion of duplicates, and papers that were judged irrelevant to the present study. Following researcher discussion of the topics to be addressed in the review, a further 53 references were judged irrelevant and it was decided to exclude 2 references from conferences and 10 from unpublished dissertations. 170 articles were ultimately deemed relevant and suitable for inclusion in the review.

2.3 Reviewing the articles

As there were a large number of articles, a small team of academic 'readers' were recruited from departmental staff with an interest in the subject of the study and a proforma (table 3) was designed for recording the details of documents as they were reviewed. Papers were distributed amongst the readers who, after reviewing an article, completed and attached a proforma, thus providing relevant details and a summary of the main points of the paper. Articles were then filed until all the papers had been read and summarised. Of the 170 papers reviewed, 117 had diagnostic aspects of dementia as their main subject and 12 papers focused mainly on the needs of people with learning disabilities who develop dementia. Only 9 papers focused mainly on models of support and there were no papers which focused only on ways in which differing service sectors become the recognised priority service. This subject was however, included in 24 of the 32 'mixed focus' papers. Mixed focus papers also accounted for further discussions on diagnosis (18 papers), needs (25 papers) and models of support (25 papers).

Table 3: EXAMPLE OF PROFORMA	
Question number	Question
1	Title of article/report
2	Author(s)
3	Year of publication
4	Journal or report details
5	Identified via (electronic database or hand search)
6	Areas addressed by the study: <ul style="list-style-type: none"> - Detection or diagnosis of dementia - Needs - Models of support - Service sector responsibilities - Other
7	Is the paper: <ul style="list-style-type: none"> - Reporting on research - A literature review / opinion paper / report - Other
8	Methodology (design used): <ul style="list-style-type: none"> - Quantitative - Qualitative - Mixed methods
9	Methods of data collection
10	Sample size and characteristics
11	Key findings
12	Recommendations
13	Study limitations
14	Any other comments
15	Reviewed by

3. RESULTS AND DISCUSSION

To enable readers to access information relating to each question, details from significant papers are set out in the form of tables. A commentary is provided in which key facts relevant to each question are highlighted and some conclusions are drawn.

3.1 Detection and/or diagnosis of dementia

Sixty nine percent (n=117) of all papers included in this literature review related to the detection or diagnosis of dementia in people with learning disabilities. This is not a straightforward process (table 4) partly due to lack of baseline assessments taken before the person with learning disabilities displayed any symptoms of dementia type illness and also due to the lack of a specific assessment tool for use with this population.

Table 4: PAPERS ON DIFFICULTIES WITH DIAGNOSING DEMENTIA			
Author	Study type	Main findings	Main recommendations
LeBlanc, L. A. & Matson, J. L. (1997)	<ul style="list-style-type: none"> Review of literature on assessment and treatment of mental health and behavioural problems in elderly people with a learning disability 	<ul style="list-style-type: none"> Current diagnostic criteria for dementia are not really suitable for older people with learning disabilities In individuals with profound and multiple learning disabilities and communication difficulties more focus needs to be placed on adaptive function rather than on cognitive function 	
Markar, T. N. <i>et al.</i> (2006)	<ul style="list-style-type: none"> Report on a pilot project to evaluate the usefulness of establishing a specially designed memory clinic for the assessment and diagnosis of dementia in people with learning disabilities 	<ul style="list-style-type: none"> Use of min-mental test unsuccessful in this study Assessment at generic memory clinics and use of mini mental test appropriate for only a few individuals with borderline/very mild learning disability Mini mental test recommended by NICE guidelines for treatment with anti-dementia drugs is only suitable for those with borderline or very mild learning disability 	<ul style="list-style-type: none"> Clinical assessments need to involve families/carers in identifying symptoms suggestive of dementia Information re availability of memory clinics should be disseminated to various establishments e.g. residential and day care services, to enable carers to make referrals early Majority of individuals with learning disabilities need to be assessed by professionals with expertise in this field and preferably at specialist memory clinics identified for this purpose
McCarron, M. (2005)	<ul style="list-style-type: none"> Opinion paper looking at challenges in dementia screening and diagnosis 	<p>Difficulties in dementia diagnosis:</p> <ul style="list-style-type: none"> Lack of diagnostic scales useful for people with learning disabilities, equivalent to those used for the generic population Lack of baseline screening in memory and medical clinics Problems with memory, judgement and planning may go unidentified due to the culture of caring, causing confusion between the symptoms of normal ageing and dementia in people with learning disabilities Health co-morbidities may be present which may mimic dementia or co-exist as part of dementia 	<ul style="list-style-type: none"> Choice of instruments should be guided by the person's underlying level of learning disability and the availability of key informants who have known the person for a considerable time To ensure consistency and reliability in the application of instruments training is required either by someone who has had relevant training and/or also has the relevant clinical skills and experience in their application A combination of informant based and objective testing is preferable Longitudinal use of selected instruments will greatly enhance the

			<p>possibility of detecting changes over time</p> <ul style="list-style-type: none"> • Urgent need for training in symptom recognition for families and staff at all levels
<p>Watchman, K. (2003)</p>	<ul style="list-style-type: none"> • Examination of the lack of consistent and accurate information for service planners and providers of care for people with Down syndrome and dementia 	<p>Difficulty of making an accurate diagnosis due to:</p> <ul style="list-style-type: none"> • High staff turnover and lack of continuity of care • Lack of single accepted assessment tool • Lack of training and experience means staff less likely to pick up on treatable conditions such as depression 	

There seems no doubt that, partly due to their huge range of difficulties and disabilities, there is not one single diagnostic tool, which could accurately diagnose dementia in all people with learning disabilities displaying possible symptoms of the disease. The literature demonstrates and evaluates some of the diagnostic tools (table 5) available but stresses that baseline information must be obtained, perhaps annually from their mid twenties, concerning the usual cognitive and behavioural patterns exhibited by all individuals with Down syndrome and learning disabilities. Behavioural, cognitive and other changes, which may be due to the onset of dementia, can be measured against this information before a diagnosis is attempted.

Author	Study type	Main findings	Main recommendations
<p>Burt, D. B. <i>et al.</i> (2005)</p>	<ul style="list-style-type: none"> • Longitudinal study, quantitative + clinical examinations 	<ul style="list-style-type: none"> • The specificity of the DMR and DSDS was high across all diagnostic methods, making them suitable to meet single completion diagnostic criteria 	<ul style="list-style-type: none"> • A combination of tests leads to increased sensitivity - assessment for psychiatric disorder, delayed memory decline, adaptive behaviour decline and the presence of seizures being the most fruitful
<p>Cosgrave, M. <i>et al.</i> (1998)</p>	<ul style="list-style-type: none"> • Report of a test to assess the utility of the 'Test for Severe Impairment' (TSI). Test was administered to each participant 3 times and each participant was also assessed using the Down syndrome Mental Status Examination 	<ul style="list-style-type: none"> • The utility of the TSI was established • Its usefulness exceeds that of the DSMSE, it is easier to use and less time consuming and can extend to subjects with severe learning disabilities 	<ul style="list-style-type: none"> • Further work to establish cut off scores for dementia and annual rate of change scores for those with dementia is ongoing
<p>Dalton, A. J. <i>et al.</i> (2002)</p>	<ul style="list-style-type: none"> • Comparison of 5 studies evaluating the usefulness, reliability and validity of the 	<ul style="list-style-type: none"> • MOSES appeared to be a useful and practical behaviour rating scale for the assessment of 	<ul style="list-style-type: none"> • Comparison of MOSES depression subscale with other methods for the evaluation of

	<p>MOSES scale in the assessment of change in ageing persons with learning disabilities</p>	<p>changes in behaviour of aged persons with learning disabilities</p> <ul style="list-style-type: none"> • Persons with Down syndrome suspected of showing symptoms of ATD could be differentiated on the basis of their scores from other persons with learning disabilities • Scale can be used in clinical settings to provide a baseline • Demonstrated longitudinal value and useful adjunct to diagnosis • It was possible to distinguish persons with clinically diagnosed depression from those with other diagnoses, particularly ATD 	<p>depression in adults with learning disabilities</p>
<p>Deb, S. & Braganza, J. (1999)</p>	<ul style="list-style-type: none"> • Comparison of rating scales for the diagnosis of dementia in adults with Down syndrome 	<ul style="list-style-type: none"> • For subjects who were in an advanced stage of dementia, clinicians were able to make the diagnosis confidently and there was good corroboration between the clinician's diagnosis and that made according to the DMR and DSDS criteria • The discrepancy in the diagnosis of dementia according to the 3 categories (clinician, DSDS and DMR) was not prominent in those subjects who were thought to be in an early stage of dementia. • Good agreement between the rates of diagnosis of dementia according to the DMR and DSDS was observed 	<ul style="list-style-type: none"> • Although observer-rated scales fared better than direct neuropsychological tests in this study a combined approach using both methods may be required for the diagnosis of dementia in people with learning disabilities
<p>Evenhuis, H. M. (1996)</p>	<ul style="list-style-type: none"> • Evaluation of Dementia questionnaire for persons with mental retardation • Questionnaire completed annually over 5 year period by nursing staff 	<ul style="list-style-type: none"> • Changes in the Sum of Cognitive Scores are the most specific criterion for a diagnosis of dementia • The SCS should be combined with SOS when considering the diagnosis • A diagnosis based on DMR scores could be made in all cases prior to or simultaneously with the clinical diagnosis • High premorbid scores as a result of severe learning disability combined with other disabilities may hamper a diagnosis based on DMR scores 	<ul style="list-style-type: none"> • The use of single completion of DMR for research purposes is <u>not</u> recommended because of the use of many different methods measuring functional levels of learning disability throughout the world. • Interpretation of score changes over time will always produce the most valid results • Further studies on a much larger sample are needed in order to more fully investigate the

		<ul style="list-style-type: none"> • Specific aetiologies of dementia may also reduce diagnostic accuracy of DMR • The DMR can never be as sensitive as a skilful psychiatric examination. It was not designed to replace careful medical examination 	<p>circumstances in which results are likely to be inaccurate</p>
Hoekman, J. & Maaskant, M. A. (2002)	<ul style="list-style-type: none"> • Analysis of results for comparison of instruments for the diagnosis of dementia in people with learning disabilities and Down syndrome 	<ul style="list-style-type: none"> • Instruments used were: DMR; CLD; and DMTS • Agreement amongst the 3 scales used is very low • Instruments do not agree which adults can be regarded as having or not having dementia 	<ul style="list-style-type: none"> • Never advisable to use a single instrument to diagnose dementia in people with learning disabilities and Down syndrome Family/direct carers need to be able to recognise symptoms of dementia
Hon, J. <i>et al.</i> (1998)	<ul style="list-style-type: none"> • Evaluation of a Rivermead memory and behavioural tests (Children's version) for adults with Down syndrome 	<ul style="list-style-type: none"> • 21 participants were unable to perform most of the test because of pre-existing severe/profound learning disabilities or severe sensory problems • The 45+ age group performed significantly worse on memory tests than the younger group 	<ul style="list-style-type: none"> • For those with mild/moderate learning disabilities the Test is a useful measure of memory function
Hon, J. <i>et al.</i> (1999)	<ul style="list-style-type: none"> • Analysis of assessments of older people with Down syndrome using tests and interview data 	<ul style="list-style-type: none"> • Most adults with Down syndrome can be effectively assessed using CAMCOG although some subscales may require modification • CAMCOG has a wide range of scores so could be used to study cognitive decline over time • Total and subscales scores were found to be strongly related to age with older participants performing worse than the younger ones 	<ul style="list-style-type: none"> • For the older population with Down syndrome the presence of pre-existing learning disabilities means that a combination of established neuropsychological assessments looking at changes characteristic of dementia plus an informant interview are invariably required to make a diagnosis of dementia
Kay, D. W. K. <i>et al.</i> (2003)	<ul style="list-style-type: none"> • Report of preliminary evaluation of Prudhoe Cognitive Function Test (PCFT) to assess cognitive function in adults with Down syndrome. Main aim was to develop an instrument to improve the clinical diagnosis of dementia and to examine its correlation with characteristic neuropathology 	<ul style="list-style-type: none"> • The degree of learning disability based on the SBIS was strongly correlated with the PCFT. This was expected as both tests were designed to measure cognitive function. There was highly significant correlation of both with the ABS showing a strong cognitive component in adaptive behaviour • Floor effects were less marked on the ABS which discriminated better among subjects with low scores making the ABS 	<ul style="list-style-type: none"> • Direct assessment is likely to be of particular value in the absence of an informant who has cared for the subject for at least a year, or when physical rather than cognitive disability is the cause of impaired function • A combination of cognitive testing and behavioural evaluation would be particularly appropriate in the presence of severely defective or absent speech or severe

		seem superior in this respect	hearing loss
Mohr, C. & Gray, K. M. (2005)	<ul style="list-style-type: none"> Report of review of publications under the broad title 'Assessment in intellectual disability' Assessment for dementia was one of the areas covered in the review 	<ul style="list-style-type: none"> Researchers are using increasingly sophisticated psychiatric analyses and refining the nature and purpose of tools for a range of clinical purposes DMR identified as most promising screening tool 	<ul style="list-style-type: none"> High demand for carer completed instruments, to be used alongside scales and tools used by professionals
Prasher, V. P. <i>et al.</i> (2004)	<ul style="list-style-type: none"> Report on use of Adaptive Behaviour Dementia Questionnaire (ABDQ) to screen for dementia in Alzheimer's Disease in adults with Down syndrome 	<ul style="list-style-type: none"> ABDQ can be completed on all older adults with Down syndrome irrespective of the underlying learning disability or degree of test compliance It has good reliability, validity and accuracy and has been shown to be a good predictor for the development of ATD in adults with Down syndrome 	<ul style="list-style-type: none"> Diagnosis of ATD in adults with learning disabilities requires further research Investigation of ABDQ in areas not covered by present study
Prasher, V. P. (1997)	<ul style="list-style-type: none"> Assessment of validity of the Dementia Questionnaire for Persons with Mental Retardation in screening for dementia in 100 adults with Down syndrome 	<ul style="list-style-type: none"> Changes in criteria of DMR questionnaire are required for use in Down syndrome population Using modified criteria described in article, sensitivity and specificity were found to be high (82%). DMR questionnaire, using modified criteria can aid screening for dementia in Down syndrome population 	<ul style="list-style-type: none"> Instrument must be used in conjunction with an appropriate clinical assessment Instrument has potential to aid further research into ageing in people with learning disabilities
Schultz, J. <i>et al.</i> (2004)	<ul style="list-style-type: none"> Report on evaluation of screening tools for dementia in older adults with learning disabilities 	<p>Tests were conducted using the following instruments:</p> <ul style="list-style-type: none"> Memory – pair associated learning tasks DSDS DMR Specifically developed uni-mental status exam (Schultz) Reiss screen for maladaptive behaviour Demographic health questionnaire Index subjects assessed as having more cognitive deficits than control Index subjects rated as having more dementia symptoms The two dementia scales were highly correlated suggesting that they assess similar elements of dementia 	<ul style="list-style-type: none"> The observed significant relationship between scores on The Schulz mini-mental status exam and the pair associated learning task on the one hand and the diagnosis of Down syndrome on the other is of potential clinical importance The potential overlap between depression and dementia may cause people with learning disabilities to be mis-diagnosed with dementia rather than as having depression Studies using both dementia instruments and following subjects longitudinally may help to clarify which of these instruments is more

		<ul style="list-style-type: none"> • The 2 dementia scales were useful in distinguishing between groups with and without dementia • DMR slightly more effective 	effective
Strydom, A. & Hassiotis, A. (2003)	<ul style="list-style-type: none"> • Report of literature review of alternative screening instruments for dementia in learning disabilities 	<ul style="list-style-type: none"> • 2 tests evaluated as useful: <ul style="list-style-type: none"> • Dementia questionnaire for people with mental retardation (DMR) • Dementia scale for Down syndrome (DSDS) • The Test for Severe Impairment and the Severe Impairment battery show promise as screening instruments but need further evaluation 	<ul style="list-style-type: none"> • Results need to be treated with caution when single instruments are used to screen for dementia • Need for longitudinal work to measure changes in cognitive function over time. This is increasingly important since the introduction of anti dementia drugs
Thompson, S. B. N. (2001)	<ul style="list-style-type: none"> • Report on evaluation of 5 psychological tools for their use in assessing dementia in people with Down syndrome 	<ul style="list-style-type: none"> • Wechsler test – useful measure for comparison of same individual over time • Raven Test – particularly useful as it can provide an equivalent IQ score without floor and ceiling effects. Can also provide a measure of visual spatial ability and problem solving ability • MEAMS – useful as an initial screening tool for people with Down syndrome. Has been shown to be valid and reliable • Hampshire Social Services Test – designed specifically for people with learning disabilities this tool is particularly sensitive in identifying deficits in cognitive and social abilities. Used with MEAMS and DMR yields important results in assessment of dementia • DMR- specifically designed for people with learning disabilities. Used in conjunction with standardised tools provides important information for assessing dementia in people with Down syndrome 	<ul style="list-style-type: none"> • All 5 screening tools were recommended for use with Down syndrome despite reservations in their original implementation because of their validity and overall usefulness in profiling cognitive abilities of people who have Down syndrome and suspected dementia
Tsiouris, J. A. & Patti, P. J. (1997)	<ul style="list-style-type: none"> • Report on drug treatment for adults with DS presenting with dementia or pseudo dementia and depression • Referrals were made for 	<ul style="list-style-type: none"> • The key to making a diagnosis of dementia in persons with DS is the exclusion of other possible causes of functional deterioration • The D.E.M.E.N.T.I.A. 	<ul style="list-style-type: none"> • If a diagnosis of dementia is made advocacy may be necessary to ensure a high quality service is provided • All efforts must be made

	<p>the following reasons:</p> <ul style="list-style-type: none"> • To confirm diagnosis of dementia because of decline in ADL skills and cognitive decline • To evaluate and diagnose treatable conditions associated with the decline • To obtain recommendations for treatment of behavioural problems 	<p>approach is a useful diagnostic tool for ruling out other causes as follows:</p> <ul style="list-style-type: none"> • Depression and other psychiatric problems • Environmental problems • Malignancy • Endocrine and metabolic • Neurological • Toxin • Infection • Accident • Formal diagnosis after other causes have been ruled out should be through a combination of history taking, physical examination and psycho geriatric assessment 	<p>to treat intercurrent medical conditions as they arise and to support the person in their usual accommodation as long as possible.</p>
Witts, P. & Elders, S. (1998)	<ul style="list-style-type: none"> • Report on examination of the utility of the Severe Impairment battery in assessing cognitive ability in people with Down syndrome 	<ul style="list-style-type: none"> • Test retest reliability of the Severe Impairment Battery was high and there was correlation between SIB and the Vineland Adaptive Behaviour Scale scores • Difficulties in administration of SIB: some areas tedious and patronising for some subjects and could be frustrating for them. 	<ul style="list-style-type: none"> • It would be useful to compare performance and patterns of scoring on SIB domains between two age matched Down syndrome groups where 1 group has been independently (and blind to researchers) diagnosed as having ATD

Despite the ever increasing number of diagnostic tools which have been, and continue to be, developed to aid the diagnosis and assessment of dementia in people with learning disabilities, there is still a continuing need for vigilance on the part of carers of people with learning disabilities. Family members and staff in supported housing are likely to be among the first to notice the subtle early changes which may signal the onset of dementia in people with learning disabilities, and must be trained to recognise such symptoms and encouraged to report them to an appropriate health professional for further investigation. After a diagnosis of dementia is made, family and carers might still assist by gathering information at least annually, in order to measure the rate of any decline and thus to guide the management of individuals with dementia.

Author	Study type	Main findings	Main recommendations
Burt, D. <i>et al.</i> (1999)	<ul style="list-style-type: none"> • Longitudinal study of ageing and dementia • Questionnaires used for assessment 	<ul style="list-style-type: none"> • Scales should be used concurrently with other methods of assessment e.g. observation and informal interview, to ensure accuracy • Further investigation necessary where there is disagreement 	<ul style="list-style-type: none"> • To be a valid measure of dementia for a given individual, a scale must be able to detect declines from level of functioning obtained when the individual is presumed to be healthy

<p>Burt, D. B. & Aylward, E. H. (2000)</p>	<ul style="list-style-type: none"> Literature review and report on clinical appraisal of a battery of tests for diagnosis of dementia proposed by an International working group 	<ul style="list-style-type: none"> The battery is divided into 2 components: informant report scales and direct assessment of individual with intellectual disability It is imperative to obtain information from informants who are familiar with the individual Where possible multiple informants should be consulted Diagnoses rely heavily on the retrospective reports of informants Longitudinal administration of the test battery by a trained examiner Test results and an interpretive/descriptive summary should be kept in client's current record Certainty in the diagnosis of dementia will be greater if decline is observed on many tests from the battery and across several assessments 	<ul style="list-style-type: none"> Dementia should be diagnosed only when longitudinal data demonstrate clinically significant decline in function Performance deficits/declines associated with pre-morbid levels of intellectual disability or ageing respectively must be differentiated from those associated with dementia To meet the diagnostic criteria for dementia, documented declines on at least one memory test and at least one of the other tests of cognitive ability is required If some, but not all, of the diagnostic criteria are met, a diagnosis of possible dementia is required
<p>Hutchinson, N. J. (1999)</p>	<ul style="list-style-type: none"> Literature review – Association between DS and Alzheimer's disease 	<ul style="list-style-type: none"> Longitudinal studies demonstrate a significant increase in prevalence rates of ATD in people with Down syndrome as individuals reach their 5th and 6th decades (36.1 – 75%) 	<p>The ideal neuropsychological tests would be:</p> <ul style="list-style-type: none"> Administered at age 20 Re-administered at regular intervals Sensitive to early cognitive changes/earliest clinical indicators of a dementing process
<p>Lane, J. (2005)</p>	<ul style="list-style-type: none"> Report on medical issues and implications of the connection between Down syndrome and ATD 	<ul style="list-style-type: none"> Importance of lifelong medical surveillance to early diagnosis of ATD in people with DS Specific medical problems in people with DS and ATD include epilepsy, pressure ulcers, infections, and feeding difficulties 	<ul style="list-style-type: none"> Medical surveillance among people with DS should be ongoing and life long Treatable medical and/or mental health conditions can then be recognised and managed Use of a proactive dementia screening policy recommended for people with DS
<p>Levitas, A. S. & Silka, V. R. (2001)</p>	<ul style="list-style-type: none"> Description of methods of gathering history from caregivers and documents when conducting a Mental Health clinical assessment of persons with LD 	<p>Factors relevant to diagnosis:</p> <ul style="list-style-type: none"> History of present illness Knowledge of changes and/or precipitating events Unwanted behaviours Mood Sleep/appetite disturbance Activity level Hallucinations/delusions Suicidal or homicidal ideation Changes in level of functioning 	<ul style="list-style-type: none"> Need integration of past history and present events to understand current problem, yield a diagnosis and suggest interventions The process of obtaining history will create an active relationship between the clinician, patient and caregivers which will

		<ul style="list-style-type: none"> • Autonomic arousal (fight or flight) • Obsessions or compulsions • Signs of neuropathic processes (behavioural disturbance) • Signs of personality disorder • Sexual disorders • Developmental history • History of cognitive and communication evaluation • Medical history 	begin to make therapeutic intervention possible
McCarron, M. (2005)	<ul style="list-style-type: none"> • Opinion paper • Challenges in dementia screening and diagnosis • Tips and suggestions to assist families / carers and clinicians to understand and recognise change and be more proactive in eliciting help 	<ul style="list-style-type: none"> • How to Diagnose ATD in people with learning disabilities? • Accurate history of change by family/carers who have known the person for a long time • Main areas of decline: memory, time and place disorientation, misplacing items, language personality and mood changes, problems with day to day activities • Screening and diagnostic work-ups 	<ul style="list-style-type: none"> • Choice of instruments should be guided by the person's underlying level of LD and the availability of key informants who have known the person for a considerable time • To ensure consistency and reliability in the application of instruments training is required by someone who has had relevant training and/or also has the relevant clinical skills and experience. • A combination of informant based and objective testing is preferable • Longitudinal use of selected instruments with each person at risk will greatly enhance the possibility of detecting changes over time • Urgent need for training in symptom recognition for families and staff at all levels
Thompson, S. B. N. (1999)	<ul style="list-style-type: none"> • Report of review of literature defining and assessing dementia in people with LDS 	<ul style="list-style-type: none"> • Environmental factors can influence assessment • Interviewing close relatives in conjunction with testing can be useful 	
Wade, R. <i>et al.</i> (2003)	<p>Review of screening tools for assessing dementia in people with LD:</p> <ul style="list-style-type: none"> • Dementia Baseline Screening Process • Dementia Questionnaire for the Mentally Retarded • Adaptive Behaviour Scale for Residents in the Community 	<ul style="list-style-type: none"> • Staff needed better understanding of the nature and course of dementia and associated behaviour • Using structured assessment tools enabled residential care staff to gather information prior to referral so that less time is wasted when a referral is received and referrals that are more appropriate are made • Structured assessment enabled staff to gather routine baseline data on the target 	

		<p>group of clients to enable more accurate monitoring by the service of any subsequent deterioration</p> <ul style="list-style-type: none"> • This aspect of the service has been developed and maintained within the existing hours of an assistant clinical psychologist, highlighting that the approach is achievable within limited resources • Funding sources to develop and extend this role are being sought 	
Watchman, K. (2003)	<ul style="list-style-type: none"> • Reports on the development of a guide for GPs in the diagnosis of dementia in people with Down syndrome 	<ul style="list-style-type: none"> • A quick reference guide (it's Your Move) was aimed at GPs to assist them in diagnosing dementia in people with DS • Stresses importance of: <ul style="list-style-type: none"> • Early diagnosis • Need for baseline assessments • Encouraging greater awareness of health needs of people with DS, many health conditions are treatable 	<ul style="list-style-type: none"> • Adults with DS and their carers have a right to know their diagnosis • Early detection of other treatable, conditions can improve quality of life • Resources similar to 'It's Your Move' should be made widely available to GPs to enable health issues in people with DS to be addressed quickly

Table 5 lists some of the studies, which stress the importance of both early and longitudinal assessments by carers for the diagnosis and management of dementia. If family and carers are expected to observe changes which might signal the onset of dementia, they need some knowledge of the signs and symptoms which might affect people with learning disabilities at this stage in their lives. Table 6 lists some of the studies which discuss these, and it should be noted that they are not invariably the same as the signs and symptoms which signify the onset of dementia in the non disabled population. It is also interesting to note that signs and symptoms in people with Down syndrome and dementia may not be the same as those in people with other learning disabilities and dementia (Cooper and Prasher,1998).

Table 7: PAPERS ON THE SIGNS AND SYMPTOMS OF DEMENTIA IN PEOPLE WITH LEARNING DISABILITIES			
Author	Study type	Main findings	Main recommendations
Ball. <i>et al.</i> (2006)	<ul style="list-style-type: none"> • Longitudinal quantitative study • Participants first assessed in 1994, followed up after 18 months and reassessed after a further 5 years • Medical history, and assessment using CAMDEX 	<ul style="list-style-type: none"> • Personality and behavioural changes (PBC) mark the preclinical stage of AD in people with DS • These changes occur in the absence of prominent functional memory decline unlike the general population with AD • Individual with DFT significantly more likely to progress to 	<ul style="list-style-type: none"> • Recognition of PBC as possible early signs of AD in people with DS may be the key to early intervention and improved prognosis

	and CAMCOG	<p>diagnosis of AD over 5 years than those without</p> <ul style="list-style-type: none"> • Individuals with PBC significantly more likely to progress to DFT or AD than those without 	
Cooper, S. A. (1997)	<ul style="list-style-type: none"> • Assessment using Behaviour checklist and Present Psychiatric State rating scale, combined with demographic information, physical assessment, drug history and review of psychiatric case notes. 	<ul style="list-style-type: none"> • Some maladaptive behaviours were significantly more prevalent in those diagnosed with dementia • These included lack of energy; sleep disturbance; agitation; incontinence of faeces and urine; excessively uncooperative; mealtime/feeding problems; irritability and verbal aggression 	<ul style="list-style-type: none"> • Future research should measure the outcomes of pharmacological, psychological, and social care plans in the management of maladaptive behaviours associated with dementia in order to inform clinical practice
Cooper, S. A. & Prasher, V. P. (1998)	<ul style="list-style-type: none"> • Quantitative analysis of dementia assessments using various schedules and questionnaires 	<ul style="list-style-type: none"> • Comparison of maladaptive behaviour and psychiatric symptomatology between a group of people with DS and dementia and another group with other LDs and dementia • Those with DS had a higher prevalence of low mood, restlessness, excessive over activity, disturbed sleep, being excessively uncooperative and auditory hallucinations • The group with other LDs showed a higher frequency of aggressive behaviours 	<ul style="list-style-type: none"> • Future research should examine the non cognitive symptoms of dementia in both people with DS and people with other LDs • The evaluation of treatment approaches would usefully contribute to existing knowledge
Cosgrave, M. <i>et al.</i> (1999)	<ul style="list-style-type: none"> • This was part of a longitudinal study to find the determinants of aggression, and adaptive and maladaptive behaviour in older people with and without dementia 	<ul style="list-style-type: none"> • Subjects with dementia were older by 7-9 years (average 55 years) • There was no increase in the prevalence of behaviour disturbance in those with dementia, contrary to findings in the general population • Self-abusive behaviour was associated with the presence of dementia as rated with the ABS • The presence of dementia is not predictive of aggression or maladaptive behaviour in people with DS • Poorer cognitive function predicts lower levels of adaptive behaviours 	<ul style="list-style-type: none"> • Longitudinal studies are required to validate the outcomes of this study • Services need to concentrate on providing extra caregiver support since the functional ability of subjects decline with the presence of dementia
Cosgrave, M. P. <i>et al.</i> (2000)	<ul style="list-style-type: none"> • 5-year longitudinal study • The following assessments were administered once each year for the 5 year follow up period • Test for Severe Impairment 	<ul style="list-style-type: none"> • Earliest recognisable symptoms were memory loss, spatial disorientation, and loss of independence particularly in personal hygiene 	<ul style="list-style-type: none"> • Increase in staff numbers and adaptations to premises may be required if subjects are to remain in the community • Specialised hospice type units appear to be the most suitable accommodation for subjects with end stage

	<ul style="list-style-type: none"> • Daily Living Skills Questionnaire • Checklist for Early Signs of Dementia 		dementia
Crayton, L. <i>et al.</i> (1998)	<ul style="list-style-type: none"> • Analysis of various tests which might indicate ATD to compare results between age groups 	<ul style="list-style-type: none"> • Prior analysis in respect of global impairment and age specific receptive/expressive communication showed no obvious differences between age groups • There were signs of early memory impairment across the cohort • Those over 50 showed memory impairments, but findings could not be unequivocally attributed to ATD • The use of sensitive neuropsychological tests identify subtle cognitive deficits in older adults with DS 	<ul style="list-style-type: none"> • There is a need for sequential assessments identify the significance of cognitive deficits and to demonstrate any decline
Dalton, A. J. & Fedor, B. (1998)	<ul style="list-style-type: none"> • Development of a 62 item dyspraxia scale adapted for use with people with DS • Scale then utilised in a longitudinal study; (3.5 years) to show progressive dyspraxia (as a symptom of ATD) begins earlier in people with DS than the general population 	<ul style="list-style-type: none"> • After 3.5 years the 'old' group of people with DS were performing at a slightly lower level in all areas measured • Dyspraxia in persons with DS aged 50+ indicates presence of early dementia 	<ul style="list-style-type: none"> • Tests must be valid and reliable with high specificity and sensitivity for detecting ATD in people with DS They need to be followed up with independent diagnosis based on clinical evaluation
Deb, S. (2003)	<ul style="list-style-type: none"> • Report of literature review on prevalence of dementia in people with DS 	<ul style="list-style-type: none"> • The main symptoms of dementia among people with DS are: forgetfulness, confusion, apraxic symptoms, speech and language problems, slowness, loss of skills, problems with socialising, lack of confidence, obsession, sleep problems, balance problems, emotional problems, hallucinations, delusions and illusions, loss of interest, covering up and hypochondriasis 	<ul style="list-style-type: none"> • There is a need to develop appropriate instruments for use with individuals displaying pre-existing severe cognitive impairment in the detection of dementia in people with LD
Devenny, D. A. <i>et al.</i> (2000)	<ul style="list-style-type: none"> • Longitudinal study • Comparing amounts of cognitive decline among 66 individuals with DS who were healthy on entry into the study. 	<ul style="list-style-type: none"> • Possible 3 stage cognitive decline: preclinical; early and middle • Adults with DS and possible ATD showed significant decline in cognitive abilities • Cognitive decline associated with the early and middle stages of ATD involved progressively more areas of functioning • The number of cognitive areas 	<ul style="list-style-type: none"> • Future studies need to include measures which are more focused with respect to the underlying cognitive processes and to include large numbers of individuals who have been followed longitudinally • Researchers need to indicate the stage of decline of affected individuals. This will help

		<p>involved was related to the severity of decline obtained from a general descriptive account based on caregiver interviews</p> <ul style="list-style-type: none"> • Individuals who showed significant declines but who had not received a diagnosis of dementia showed concomitant declines in interspatial organisation and new learning • Age associated decline in people with DS in 6th decade not inevitable • Severity of dementia related to progressive deterioration of areas of cognitive function • Memory loss was a predominant symptom in all participants showing decline 	<p>determine the duration of ATD and its natural history in this population.</p> <ul style="list-style-type: none"> • WISC-R can be used to distinguish between early stage dementia and declines related to 'normal' ageing and life-long cognitive deficits. To do this, baseline data must be obtained when individual is healthy
Devenny, D. A. <i>et al.</i> (2002)	<ul style="list-style-type: none"> • Analysis of 'cued recall' tests to examine memory decline 	<ul style="list-style-type: none"> • Memory decline can occur several years prior to the identification of ATD • Longitudinal data and converging measures indicated the possibility that 13 of the participants were in a pre dementia stage of decline 	<ul style="list-style-type: none"> • The usefulness of the CRT as a screening test for early memory deficits needs to be confirmed by following these participants for an extended period of time and also by studying an independent sample
Devenny, D. A. <i>et al.</i> (1996)	<ul style="list-style-type: none"> • Analysis of results of annual testing using 4 test instruments undertaken with every participant over a six year period 	<ul style="list-style-type: none"> • The performance of participants with DS was indistinguishable from their peers with other LDs except in the SRT • Adults with DS may experience premature but otherwise normal ageing • Individuals with DS had short term memory performance deficits in the visual modality suggesting a more pervasive deficit in memory processing that appears non age related • Individuals with a diagnosis of ATD showed the greatest decline in measures of long term memory • Poorer performance in people with DS over 50 years of age is suggestive of precocious ageing rather than ATD 	<ul style="list-style-type: none"> • Longitudinal studies spanning more than 5 years are needed to document the detailed course of both normal ageing and ATD • Active lifestyles may delay cognitive deficits expected from neuropathological changes in this population
Friedman, O. & Brown, I. (2001)	<ul style="list-style-type: none"> • Pilot study on assessment of dementia in people with DS, in which caregivers were asked to fill in an Assessment protocol • All caregivers had known the person with DS for at least 6 months 	<ul style="list-style-type: none"> • Data supports the idea that not all people with DS who have developed neuropathological brain changes associated with ATD actually show clinical symptoms of dementia • The onset of symptoms of dementia may not appear all at the same time and vary among individuals • Observed memory decline may be the most important clinical symptom in people with DS 	<ul style="list-style-type: none"> • Individual traits in declines highlighted by use of this tool can be used to develop individually specific care plans • There is a need to examine closely the onset of symptoms associated with ATD in people with DS

		<ul style="list-style-type: none"> under age 40 Social and behavioural declines might contribute most strongly to the overall diagnosis for people over age 40 Some declines may describe a 'pre-clinical' stage of dementia, particularly in memory 	
Hassiotis, A. <i>et al.</i> (2003)	<ul style="list-style-type: none"> Description of memory clinic for people with LDs including description of assessment scales and examinations used 	<ul style="list-style-type: none"> 5 subjects with DS were diagnosed with ATD at assessment A further 2 subjects with DS were diagnosed with ATD at follow up Main symptoms were in adaptive functioning, sleep disturbance and behavioural problems No subjects without DS were diagnosed with ATD Those with DS often scored on the UPDRS due to clumsiness and dysarthria Further reviews of those with ATD showed marked deterioration in mobility and behaviour as well as increases in seizures in 2 subjects with epilepsy 	<ul style="list-style-type: none"> An additional test to simplify assessment of cognitive function has been added to the battery of tests used (Test for Severe Impairment TSI) Memory clinic could become an important resource for research and training of health professional and carers
Holland, A. J. <i>et al.</i> (2000)	<ul style="list-style-type: none"> Results of 2 assessments with 18 month interval on people with DS A modified version of the Cambridge Examination of Mental Disorders of the Elderly Informant Interview was used to determine the rate of changes in memory, personality, general mental functioning and daily living skills 	<ul style="list-style-type: none"> 1st assessment – changes reported were predominantly in behaviour and personality 2nd assessment – incidence rates for frontal lobe dementia were high, mainly in the younger groups ATD was higher in the older groups Symptoms of frontal lobe dementia in younger persons with DS tend to precede ATD at a later date 	<ul style="list-style-type: none"> Development of safe and effective treatments for ATD, combined with good clinical data on the early signs and causes of dementia in people with DS should ultimately ensure potential for better outcomes for people with DS in later life
Hutchinson N. J. (1999)	<ul style="list-style-type: none"> Literature review Association between DS and ATD 	<ul style="list-style-type: none"> ATD in people with DS progresses more rapidly Average duration of symptoms from onset to death 3-6 years compared to 8-15 years in general population ATD in people with DS first manifests itself in the form of changes in behaviour, mood and personality rather than the cognitive deficits found in the general population This difference is more marked, the more severe the degree of LD The last stage of ATD in 	<p>The ideal neuropsychological tests would be:</p> <ul style="list-style-type: none"> Administered at the age of 20 Read ministered at regular intervals Sensitive to early cognitive changes/earliest clinical indicators of a dementing process

		<p>people with DS has been associated with high incidence of late onset epilepsy with prevalence rates as high as 89% compared to 10% of general population</p> <ul style="list-style-type: none"> • This is reported as a strong indicator of the dementing process and a prognostic indicator with people with DS surviving no more than 3 years from the onset of seizures • Criteria for dementia in people with learning disabilities: <ul style="list-style-type: none"> • Memory decline • Decline in other cognitive function • Decline in awareness of one's environment • Decline in emotional control, motivation and social behaviour • Exclusion of other causative factors • Other factors which may be responsible for cognitive/ behavioural decline include hypothyroidism, sensory impairment, sleep disorders, mood disorders, Parkinson type degeneration, cardiovascular degeneration 	
Huxley, A. <i>et al.</i> (2005)	<ul style="list-style-type: none"> • Comparison of challenging behaviour in 2 groups of people with DS one group with dementia and one group without dementia 	<ul style="list-style-type: none"> • Difference in frequency of aberrant behaviour was significant in terms of lethargy, and hyperactivity and close to significant for stereotypy and irritability • Difference was not significant for inappropriate speech • Adults with DS who show signs of dementia are more likely to display challenging behaviour more frequently and more severely than those without evidence of dementia 	<ul style="list-style-type: none"> • Routine assessments for dementia should be offered to all people with DS at a certain age • To raise awareness that challenging behaviour in older persons with DS may be attributable to the onset of symptoms of ATD
Jozsvai, E. (2006)	<ul style="list-style-type: none"> • Report on comparison of behavioural and psychological symptoms of dementia in people with DS (DS-D) and in people without history of LD (NORM-D) 	<ul style="list-style-type: none"> • All target behaviours occurred with higher frequency in the DS-D group than in the NORM-D group with the exception of attention seeking behaviour. Only non compliance occurred at a significantly higher frequency • The inferred state of insomnia was reported as significantly more severe in the NORM-D group • Property destruction and non compliance were reported as more severe in the DS-D group 	<ul style="list-style-type: none"> • Compliance can be enhanced by behaviour management techniques including visual and verbal prompting, restructuring environment to facilitate occurrence of desired behaviours and enhance physical assistance • Property destruction can be reduced by enhanced supervision and allowing some repetitive destructive behaviours in a designated environment and location
Krinsky-	<ul style="list-style-type: none"> • Report on use of 	<ul style="list-style-type: none"> • Verbal explicit memory is 	<ul style="list-style-type: none"> • SRT has promise as a

<p>McHale, S. J. <i>et al.</i> (2002)</p>	<p>SRT to examine changes in memory that occur with early stage dementia in adults with DS and comparison of changes with 'normal' ageing</p>	<p>affected during early stage ATD in adults with DS</p> <ul style="list-style-type: none"> • In addition to the ability to store new information, the ability to retrieve stored items was significantly impaired in adults with early stage ATD • SRT showed substantial decline for 14 adults with DS who, in the course of the study, came to meet the criteria for early stage ATD • The rate of 'normal' age associated decline in verbal explicit memory was clearly distinguishable from the more dramatic declines that accompanied or anticipated a diagnosis of ATD 	<p>clinical tool which might be included in a dementia assessment battery</p> <ul style="list-style-type: none"> • Any single measure needs to be used in conjunction with other measures • Because other conditions mimic dementia, comprehensive evaluations extending over time should be performed, and all treatable conditions addressed before a diagnosis of ATD is made in any adult with LD
<p>Millichap, D. <i>et al.</i> (2003)</p>	<ul style="list-style-type: none"> • Examination of the hypothesis that a functional relationship exists between social environmental events and behavioural excesses in individuals with DS and dementia 	<ul style="list-style-type: none"> • Behaviours not random but were related to environmental events • Changes in the probability of staff and peer contact occurred in the periods preceding and following onset of behaviours • Where non-verbal behavioural excesses occurred there would be a relationship with co-occurring environmental events with significant relationships 	<ul style="list-style-type: none"> • Descriptive analysis is a potentially useful method of examining behavioural excesses and deficits in persons with DS and ATD • Future study should include temporal information and application of an experimental analogue phase
<p>Moss, S. & Patel, P. (1997)</p>	<ul style="list-style-type: none"> • Collection of data on health and functional ability of 101 people with LD over age 50 identified 12 as suffering from dementia. This data is compared with that from non dementia sufferers • Methods used included physical health assessment • Mental health assessment (PASS-ADD) with key informants • Parts 1 and 2 of ABS 	<ul style="list-style-type: none"> • Poorer physical health for dementia sufferers • People who were confirmed as suffering from dementia were more likely to score positive on loss of interest, sleep difficulty, irritability, slowness and poverty of speech, but likely to score negative on depressed mood and delayed sleep • Significant differences in some areas of adaptive behaviour scale • People suffering from dementia had a greater number of chronic physical health problems and chronic disability resulting from these • Capacity for self directed activity lower in dementia group • Dementia group also had a reduced capacity for enjoyment, were more irritable and were prone to violence 	<ul style="list-style-type: none"> • Regularly updating of local prevalence of dementia necessary to support the planning of service need • Individuals needs must be responded to • Service providers and researchers need to give attention to the needs of those with dementia • Results support the view that needs can be dealt with by generic services specialising in dementia
<p>Nelson, L. D. <i>et al.</i> (2001)</p>	<ul style="list-style-type: none"> • Investigation of the possibility that emotional changes in people with DS over time were associated with brain atrophy on MRI scan and the 	<ul style="list-style-type: none"> • Abnormal MRI results/frontal reflex findings associated with specific changes in emotional and cognitive functioning, along with decline in receptive vocal knowledge • Adults with DS who demonstrated these signs 	

	presence of pathological reflexes on neurological examination	appeared to have a particular symptom complex characterised by dysphoric mood, apathy or indifference and problems in social discourse	
Oliver, C. <i>et al.</i> (1998)	<ul style="list-style-type: none"> • Report on study of age related cognitive change in people with DS 	<ul style="list-style-type: none"> • Degree of pre-existing cognitive impairment is associated with faster rate of deterioration • Cognitive deterioration index demonstrated decline in orientation, memory and learning • Deterioration in memory, learning and orientation evident only in the moderate cognitive deterioration group as opposed to those showing no or severe cognitive deterioration. In those with no cognitive deterioration dementing process has not started so no decline is seen, in those with severe cognitive deterioration 'floor' levels have been reached so no further deterioration is seen • Estimates of dementia in adults with DS based on neuropathological studies tend to be inflated as these do not always compromise intellectual functioning 	
Orange, J. B. & Zanon, M. V. (2006)	<ul style="list-style-type: none"> • Review of what is currently known about the language and communication of people with DS and ATD 	<ul style="list-style-type: none"> • Receptive language skills are more severely affected than expressive language skills in ageing adults with DS • Expressive language may remain relatively intact over time and can act as a measure of overall ability level • Whether changes in receptive language are age-related, ATD-related or both remains largely unknown 	<ul style="list-style-type: none"> • More research is required on language and communication of adults with DS and ATD to establish an evidence base • There is a need for cross-sectional longitudinal experimental studies • There is a need for multi-perspective observational field studies of language and communication in adults with DA and ATD • Preliminary reports describing strategies about how to maintain communication with adults with DS and ATD need to be verified empirically
Prasher, V. P. (1996)	<ul style="list-style-type: none"> • Report on investigation into the presence of prodromal features (e.g. low mood) in adults with DS before a diagnosis of dementia is made 	<ul style="list-style-type: none"> • No obvious prodromal phase prior to diagnosis of dementia in adults with DS • Early signs of dementia were present prior to diagnosis of dementia • Significant decline in adaptive behaviour skills occurs at this time • Findings differ from those for the general (non LD) 	<ul style="list-style-type: none"> • Further research is needed into whether prodromal changes do occur in people with LDs but are not detected due to the underlying impairment

		population where low mood, irritability and behavioural changes occur prior to a diagnosis of dementia	
Roeden, J. M. & Zitman, F. G. (1997)	<ul style="list-style-type: none"> Report on longitudinal comparative study of subjects with DS and a control group of subjects with LD (but not DS) focusing on age related functional deterioration 	<ul style="list-style-type: none"> DS subjects over 50 show a statistically significant decline in adaptive, intellectual, memory and motor function which was absent in non DS group Decline was rapid Cognitive functions deteriorated significantly in 2.5 years, adaptive functions in 4.5 years Results compatible with other studies 	
Sung, H. <i>et al.</i> (1997)	<ul style="list-style-type: none"> Report on case studies used to identify and link symptoms associated with depression and with dementia in 3 ageing adults with Down syndrome 	<ul style="list-style-type: none"> Difficult to distinguish between depression and dementia in persons with LD due to complex expression of symptoms The combined use of qualitative and quantitative data enabled emerging patterns to be identified that hold the potential to distinguish between dementia and depression in DS Changes characteristic of normal ageing were present in all 3 subjects Symptoms of dementia included: <ul style="list-style-type: none"> Noticeable decline in cognitive function especially memory skills Gradual and persistent decline in attention span Time and direction disorientation Dramatic losses of functional competence in all aspects of adaptive behaviour Noticeable passivity with slow sluggish movements Loss of vocational skills Symptoms of depression included all the above but more conspicuously and over a shorter time Depressed subject also suffered: <ul style="list-style-type: none"> Weight loss, loss of interest in formerly pleasurable activities and reduced interaction with others 	<ul style="list-style-type: none"> Should be periodic comprehensive assessment of adults with DS to detect changes in functioning and cognition which could be indicative of either depression or dementia It will be necessary to provide appropriate services for adults with either depression or ATD as they exhibit symptoms Additional social support will help older adults with DS to maximise the possibility of reversing apparent declines in function
Temple, V. & Konstantareas, M. M. (2004)	<ul style="list-style-type: none"> Report of comparison of behavioural and emotional characteristics of Alzheimer's dementia in adults 	<ul style="list-style-type: none"> Individuals with AD only had higher total scores and more problems on the behaviour scales Individuals with DS has a lower rate of psychotic behaviour Individuals with DS were more 	<ul style="list-style-type: none"> Future comparison between similar groups could determine if the differences observed in the present study are maintained when both groups are given cognitive

	with and without DS	likely to engage in physical movement	enhancers rather than the AD group only
Visser, F. E. <i>et al.</i> (1997)	<ul style="list-style-type: none"> • Longitudinal study of patients with DS to determine the prevalence of ATD • Diagnosis by Early Signs of Dementia Checklist, Social Skills Inventory for the Mentally Retarded, EEG, and neuropathological examination post mortem 	<ul style="list-style-type: none"> • Difficult to differentiate between incipient dementia and normal ageing. When first symptoms are related to personality changes or signs of dyspraxia, dementia is more likely • Progressive decline was accompanied by continued deterioration in ability to perform coordinated movements • 98% who showed severe deterioration developed epilepsy • Strong correlation between clinical findings and neuropathological findings post mortem 	<ul style="list-style-type: none"> • Monitoring of cognitive functioning can be done by nurses on a regular basis • Regular EEG recordings are useful as they allow changes to be monitored visually

3.2 Needs

After a diagnosis of dementia has been made it will be necessary for services to meet a variety of changing needs, relating not only to individuals with dementia, but also to their carers and possibly, in the case of those people living in supported housing, to their peers. The papers which focused mainly or in part on these issues were divided into those which concentrated directly on the needs of clients, those which gave prominence to the needs of family and paid carers and those which considered the needs of fellow residents of individuals diagnosed with dementia.

3.2.1 Needs of people with learning disabilities who develop dementia

The papers which focus on the needs of people with learning disabilities and dementia could be approximately divided into those which concentrated on their medical needs (table 8), those, which concerned their social needs (table 9) and those papers, which discussed a mix of medical and social needs (table 10).

Table 8: PAPERS ON THE MEDICAL NEEDS OF PEOPLE WITH LEARNING DISABILITIES AND DEMENTIA			
Author	Study type	Main findings	Main recommendations
Ball, <i>et al.</i> (2006)	<ul style="list-style-type: none"> • Longitudinal quantitative study • Participants first assessed in 1994, followed up after 18 months and reassessed after a further 5 years 	<ul style="list-style-type: none"> • Personality and Behavioural Changes (PBC) mark the preclinical stage of AD in people with DS 	<ul style="list-style-type: none"> • Recognition of PBC as possible early signs of AD in people with DS may be the key to early intervention and improved prognosis

Cooper, S. A. (1997)	<ul style="list-style-type: none"> • Survey including demographic information, medical assessment of all bodily systems, drug history, PPS-LD, psychiatric case note review 	<ul style="list-style-type: none"> • High rate of psychotic symptoms • High rate of cognitive skills symptoms 	<ul style="list-style-type: none"> • It is important that these symptoms are recognised so that in future there will be better understanding and development of appropriate support and effective management strategies
Cooper, S. A. (1999)	<ul style="list-style-type: none"> • Quantitative analysis of physical and psychiatric assessments 	<ul style="list-style-type: none"> • There is an established association between physical illness/ other psychiatric disorders and dementia in the general population • This should alert psychiatrists to the need for regular physical assessments in order to optimise health for people with LDs 	
Holland, A. J. <i>et al.</i> (2000)	<ul style="list-style-type: none"> • Analysis of results of 2 assessments on people with DS with an interval of 18 months between • A modified version of the CAMDEX Informant Interview was used to determine the rate of changes in memory, personality, general mental functioning and daily living skills 	<ul style="list-style-type: none"> • 1st assessment – changes reported were predominantly in behaviour and personality • 2nd assessment – incidence rates for frontal lobe dementia were high, mainly in the younger groups • ATD was higher in the older groups • Symptoms of frontal lobe dementia in younger persons with DS tend to precede ATD at a later date 	<ul style="list-style-type: none"> • Development of safe and effective treatments for ATD, combined with good clinical data on the early signs and causes of dementia in people with DS should ultimately ensure potential for better outcomes for people with DS in later life
Lane, J. (2005)	<ul style="list-style-type: none"> • Report on medical issues and implications of the connection between Down syndrome and ATD 	<ul style="list-style-type: none"> • Importance of lifelong medical surveillance to early diagnosis of ATD in people with DS difficulties 	<ul style="list-style-type: none"> • Medical surveillance among people with DS should be ongoing and life long • Treatable medical and/or mental health conditions can then be recognised • Use of a proactive dementia screening policy recommended for people with DS • Information must be shared between professionals of all disciplines and decisions shared to maximise quality of life

<p>Mohr, C. & Gray, K. M. (2005)</p>	<ul style="list-style-type: none"> • Review of 64 publications under the broad title 'Assessment in intellectual disability' • Assessment for dementia was one of the areas covered in the review 	<ul style="list-style-type: none"> • Researchers are using increasingly sophisticated psychiatric analyses and refining the nature and purpose of tools for a range of clinical purposes • DMR identified (by Strydom and Hassiotis, 2003) as most promising screening tool 	<ul style="list-style-type: none"> • High demand for carer completed instruments, to be used alongside scales and tools used by professionals
<p>Prasher, V. P. <i>et al.</i> (2004)</p>	<ul style="list-style-type: none"> • Report of a 4 year longitudinal study of adults with DS with and without ATD to investigate the association between weight loss and Alzheimer's disease 	<ul style="list-style-type: none"> • All individuals in the dementia group had lost weight during the study period • Overall both groups had a tendency for unexplained weight loss • No significant change in the rate of weight loss for factors of age, gender, severity of LD or residence 	<ul style="list-style-type: none"> • Nutritional education programmes can be useful to manage weight loss in adults with LD • Referral to speech therapist and occupational therapist useful to diagnose possible dysphagia • Supervision by dietician useful • Further research required to investigate underlying causes of weight loss and most appropriate forms of management to prevent weight loss
<p>Tyler, C. V. & Shank, J. C. (1996)</p>	<ul style="list-style-type: none"> • Case study of person with DS and ATD 	<ul style="list-style-type: none"> • Adults with LD and severe functional decline require thorough medical, psychiatric and environmental assessment • History should routinely include questions regarding ADL, behaviour and personality changes and signs and symptoms of sleep disturbance 	<ul style="list-style-type: none"> • Ophthalmic and auditory screening should take place every 2 years • Parents and carers benefit from practical, concrete advice on the management of specific problem behaviours such as anger, aggression, wandering and sleep disturbance • Persons with DS and DT require continuing close surveillance for concurrent medical disorders such as hypothyroidism, infection, seizures, and anaemia.

3.2.2 Medical needs

Papers relating to the medical needs of people with learning disabilities and dementia (table 8) concentrate mainly on early diagnosis of dementia by medical assessment and by recognition of personality and behavioural changes. This creates a need for regular, possibly lifelong, physical and psychiatric reviews by professionals (Lane, 2005) together with knowledge by carers of the symptoms of different types of dementia and how these might affect people with learning disabilities in the initial stages of dementia. Possibly even more

important is the demand for carer-completed assessments (Mohr and Gray, 2005) either by staff in supported housing or by family members where the person with learning disabilities remains in the family home. Other medical needs concern the development and use of effective treatments for early stage dementia in people with learning disabilities, supervision of their day to day needs for nutrition, surveillance for concurrent medical conditions and involvement of ancillary medical staff in their care as the disease progresses.

Table 9: PAPERS ON THE SOCIAL NEEDS OF PEOPLE WITH LEARNING DISABILITIES AND DEMENTIA

Author	Study type	Main findings	Main recommendations
Beattie, A. <i>et al.</i> (2005)	<ul style="list-style-type: none"> Qualitative field study of marginalised groups and dementia care concentrating on younger people age < 65 and minority ethnic groups 	<ul style="list-style-type: none"> Tension between desire for services to be provided locally and small number of service users believed to constitute marginalised groups Doubt whether GPs had cultural or linguistic ability to make an accurate diagnosis Historical and pervasive wish to mislabel black people as having dementia General shortage of dementia services across the region Lack of choice of services to end-users Issues of stigma with black subjects General lack of appropriate care in mental health, day care and residential nursing home services Transport services a universal problem Low pay for care workers related to difficulties in recruiting and retaining staff Respite care was the service most required by carers Unsuitability of small number of specialist dementia services for minority groups Services rationed within a hierarchy of needs Family carers refrain from approaching services until they are unable to cope Care staff lack specialist training GPs view dementia as untreatable and thus see no point in referring people to specialist services 	<ul style="list-style-type: none"> More detailed attention should be paid to people from minority groups who develop dementia Need to develop a sophisticated sociology of impairment
Chaput, J. L. (2002)	<ul style="list-style-type: none"> Comparison of select factors found in group homes and special care 	<ul style="list-style-type: none"> Small size of group homes enhances individual care and staff-resident interactions which benefit the clients Group homes provide a 	<ul style="list-style-type: none"> Residents with DS and dementia remain in their group homes for the duration of the disease Agencies should

	<p>units to determine which is able to provide a better quality of life for people with DS and dementia</p>	<p>therapeutic philosophy of care, more individualisation, continuity of care, more personalised spaces, promote community participation, supported independence and decision making</p> <ul style="list-style-type: none"> • Group homes encourage continuation of past life styles • Staff in special care units receive higher salaries, better staff training relating to dementia, but have lower staff to client ratios (1:4 v 3:5) • Special care units are restrictive in terms of community interaction and continuation of familiar outdoor activities and there is little opportunity to leave the unit • Staffing costs are more economical in group homes 	<p>consider increasing staffing levels in group homes where a resident has dementia and providing training and education on dementia and dementia care management for staff</p>
<p>Cosgrave, M. P. <i>et al.</i> (2000)</p>	<ul style="list-style-type: none"> • 5 year longitudinal study • These assessments were administered once each year for the 5 year follow up period • Test for Severe Impairment • Daily Living Skills Questionnaire • Checklist for Early Signs of Dementia 	<ul style="list-style-type: none"> • Over the 5 year study period, the number of subjects diagnosed with dementia rose from 7 (8.75%) to 35 (43.75%) • Age related prevalence figures showed that dementia was more common with increasing age • Earliest recognisable symptoms were memory loss, spatial disorientation, and loss of independence particularly in personal hygiene 	<ul style="list-style-type: none"> • Increase in staff numbers and adaptations to premises may be required if subjects are to remain in the community • Specialised hospice type units appear to be the most suitable accommodation for subjects with end stage dementia
<p>Fisher, K. (2004)</p>	<ul style="list-style-type: none"> • Discussion of issues in caring for elderly people with LD 	<ul style="list-style-type: none"> • The ageing of the LD population has significant consequences for community resources and healthcare allocation • Ageing persons with LD may outlive their family carers and may have to live outside their (familiar) family environment from the first time • There are barriers to healthcare for these people: • Lack of knowledge • Characteristics of residential caregivers • Communication difficulties • Providers of healthcare lack time to devote to medical, social and preventative needs of PLDs • Recognition that high rates of dementia and psychiatric illness make care complex • Raising awareness among nurses and other staff of the challenges faced should 	<ul style="list-style-type: none"> • Need for education and increased exposure to special needs of these people required • Further research needed into the unique needs of this population

		improve both quality and access to care for this group of elderly people with LD	
Kerr, D. <i>et al.</i> (2006)	<ul style="list-style-type: none"> Report on a study investigating whether services are prepared to meet the needs of people with LD and dementia Study considered 3 models of care: <ol style="list-style-type: none"> 1) Ageing in Place 2) In place progression 3) Referral out 	<ul style="list-style-type: none"> Clients 'referred out' because current placement was not 'dementia ready' Night staffing problems due to dementia behaviour More training needed Need to create an enabling environment Supporting fellow residents 'Ageing in place' 	<ul style="list-style-type: none"> Better training and support for direct care staff The provision of waking night staff Improvement to the built environment Improvement to diagnostic pathways Appropriate support for co-residents Develop an 'outreach' model of care to enable people to remain in their own homes Services that can meet the needs of people referred out
McCallion, P. <i>et al.</i> (2005)	<ul style="list-style-type: none"> Pilot study comparing matched samples from foster family care providers and staff caregivers in other settings on the subjective and objective burden of care for people with LD and dementia 	<ul style="list-style-type: none"> No differences were found in caregiver subjective burden between the 2 groups Staff in group homes spent more time addressing behavioural concerns than foster families Group home staff spent more time on bathing, eating and nursing care than foster family carers Foster family carers spent more time on housekeeping and related activities 	<ul style="list-style-type: none"> Need to investigate transitions from foster family care situations when persons present with dementia May be possible to increase levels of support to keep such persons in the foster care situation. Policy makers, planners and services administrators need to be thinking about the mix of services and supports likely to sustain people with LD and AD in foster family care homes
Post, S. G. (2002)	<ul style="list-style-type: none"> Literature view and opinion paper on ethical issues surrounding care for people with LD and dementia 	<ul style="list-style-type: none"> This paper discusses background demographic info, clinical epidemiology, the ethics of care giving and other ethical issues Demography of ageing and the gap between support networks A support system for the relatively young with cognitive disabilities DS and AD scientific and clinical considerations Family caregiver response and clinical management in the terminal stage Biomedical ethics and peaceful dying The value of love and care 	<ul style="list-style-type: none"> We need to reflect more deeply on the relevant medical, ethical, legal and policy issues as they pertain to death and dying
Watchman, K. (2003)	<ul style="list-style-type: none"> Opinion paper proposing a new set of guidelines suggesting the 	<ul style="list-style-type: none"> 1) Preventable difficulties can be caused by the environment in which people with DS and dementia live (e.g. décor may be pleasing but may cause 	<ul style="list-style-type: none"> Environments can be adapted in order to maintain independence if dementia develops Environmental

	modification of the environment of adults with DS before they develop dementia. • Barriers to implementation are also discussed	confusion to the individuals) • 2) Enforced unnecessary moves may result from the above • 3) Remaining in a familiar environment is preferable • 4) Guidelines are presented on adapting the environment prior to the onset of dementia to prevent 2) and enable 3)	adaptations should not be seen in isolation but as a complement to other dementia care • Interventions should be minimal and person centred but this should not be viewed as a 'non interventionist' strategy
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3.2.3 Social needs

The papers which discuss the social needs of people with learning disabilities who develop dementia (table 9) recognise the complexities of care for this client group. Many of the papers (e.g. Fisher, 2004; Kerr, *et al.*, 2006) focus on deficiencies in services for these people. McBrien (2005) reports that 95% of people with Down syndrome and Alzheimer's disease over the age of 55 were in residential care compared to the national average of 70%. The concept of 'ageing in place', which will be further discussed in the section concerning models of support, is introduced by Watchman (2003) and by Kerr, *et al.* (2006) and 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. There is some acceptance that people in the terminal stages of dementia will require specialist care, and Post (2002) suggests a philosophical approach to the needs of this client group. Cosgrave *et al.* (2000), in a paper, which concentrates on the prevalence and early diagnosis of dementia, suggest a need for specialist hospice type units to meet the needs of people with learning disabilities in the terminal stages of dementia.

Table 10: PAPERS ON THE MEDICAL AND SOCIAL NEEDS OF PEOPLE WITH LEARNING DISABILITIES AND DEMENTIA

Author	Study type	Main findings	Main recommendations
Kalsy, S. <i>et al.</i> (2005)	<ul style="list-style-type: none"> • Description and assessment of proactive screening for dementia in older adults with LD • Appraisal of the dedicated clinical psychology service strategy within the NHS in England 	<ul style="list-style-type: none"> • Dedicated psychology services for dementia assessment can be effective in offering a defined and valuable psychological response to increasing presentation of dementia-associated behaviours among people with LD 	<ul style="list-style-type: none"> • Should get carers to contribute to assessment and intervention process, so as to ensure responsive and respectful case management for person with LD and dementia • A proactive psychology screening and multi-modal intervention model can have as its goal, the enhancement of quality of life for people with LD as they age • A dedicated service combined with interdisciplinary and cross agency working can emphasize a commitment to the core principles of choice, partnership, dignity and respect for people with DS and other forms of LD in later life
McCallion, P. <i>et al.</i> (2005)	<ul style="list-style-type: none"> • Report of literature review giving an overview of dementia issues in intellectual disability 	<ul style="list-style-type: none"> • Discusses issues concerning dementia in PLDs • Identifies 3 groups of dementia affecting older people with LD <ol style="list-style-type: none"> 1. Slow progression of dementia over 5-8 years 2. Decline may not be compressed but present at mid stage with behavioural and psychotic features 3. Decline compressed, person may progress to a stage of advanced dementia in a relatively short time e.g.1-2 years. • Group 1 should be able to 'age in place' with appropriate support • Group 2 may be able to 'age in place' with improved communication and attention to programming and environmental concerns, but may need a dementia specific environment with specialist trained staff to address additional care needs • Group 3 will require specialist nursing and palliative care offers some direction for services 	<ul style="list-style-type: none"> • Calls for more research, especially longitudinal, based on collaboration between PLDs their families, services and researchers • Recommends combining research evidence with practice • Small changes may have a big impact on the experience of dementia for people with LD and also their families and carers

<p>Reilly, E. (2005)</p>	<ul style="list-style-type: none"> • Report on research into care planning and management of people with LDs and dementia 	<ul style="list-style-type: none"> • Routine contact between medical and care management • Care planning – documentation and operationalisation of treatment strategy • Modification of treatment strategy and care plan • Accurate record keeping • Review and modification of person’s responsibilities, daily routine and environment • Assessment of needs • Neurological assessment • Physical health • Biography • Personality • Social environment • Personal and sensory environment 	<p>Key elements that should exist in the plan:</p> <ul style="list-style-type: none"> • Each care goal • How and when goal should be attained • What strategies are to be tried • Who is responsible for implementing each strategy • When the plan should be evaluated • Care plan meetings should be held at least every 6 months
<p>Service, K. P. (2002)</p>	<ul style="list-style-type: none"> • Literature review Looking at considerations in care for individuals with DS and advanced dementia 	<p>Medicaring goals:</p> <ul style="list-style-type: none"> • Comprehensive quality medical and symptom management • Continuous coordinated care • Patient/family education and support • Advance care planning • Patient/carer counselling and support • Services for end of life care • Principle of habilitation • Maintenance of skills and enhancement of wellbeing by creating a positive environment through the promotion of personal worth, basic trust and security in the environment • Palliative care does not mean ‘no treatment’ 	<p>Areas that need to be addressed include:</p> <ul style="list-style-type: none"> • Technical information • Relief • Rest • Support • Reassurance • Receipt of ongoing information • Participation • Sense of humour • Appreciation • Those who are supporting people at the end of life understand that they are no longer practicing from the science of their profession but from its art. They should note the following proverb: <i>‘Cure sometimes, relieve often and comfort always’</i>

Most papers which discuss both medical and social needs of people with learning disabilities and dementia assume a degree of interdisciplinary cooperation. Kalsy *et al.* (2005) recommend a dedicated service combined with interdisciplinary and cross agency working to meet the needs of these clients, and Davies *et al.* (2002) provide a list of needs of both clients and carers while stressing the necessity for equal access to drugs and services with the generic population (table 10). McCallion *et al.* (2005) identify three different stages in the possible progression of dementia and discuss the different needs of clients experiencing each stage, while Reilly (2005) and Service (2002) argue the need for specific goals to meet the needs of both clients and their carers.

3.2.4 Needs of carers

It is not really possible to separate the needs of people with learning disabilities and dementia from the needs of their carers, as the one obviously impacts upon the other.

Davies *et al.* (2002) illustrate this with a mixed focus paper, which considers the needs of both people with learning disabilities with dementia and their carers (table 11).

Authors	Study type	Main findings	Main recommendations
Davies, M. <i>et al.</i> (2002)	<ul style="list-style-type: none"> Description of a study identifying number of people with LD in an area in N. Ireland who were diagnosed with dementia, to collect demographic details and to profile the needs of the group 	<ul style="list-style-type: none"> Demographic: 12 subjects aged 31-50 years, 24 51-65 years 6 aged 65+ ,1 age unknown Participants were in the following residences: independent accommodation, small group residence, own home with carers, residential home, nursing home, hospital Subjects were identified as having the following additional needs: communication, mobility, deaf/hard of hearing, blind/partially sighted, epilepsy, risk to self/others, disorientation, challenging behaviour Needs (assessed depending on living arrangements): <ul style="list-style-type: none"> Current: <ul style="list-style-type: none"> Increased staffing Extra support Help to manage changes (physical behavioural and cognitive) Help to manage stress (staff) Staff training Unsuitable residences Diagnostic skills Coping skills Future: <ul style="list-style-type: none"> Higher dependency residential facility Adaptation of current residence Future care Specialist domiciliary/respite care Specialist residential nursing care Specialist reality training Ongoing diagnosis Coping with challenging behaviour 	<p>The working party made 12 recommendations in response to findings:</p> <ol style="list-style-type: none"> Comprehensive multidisciplinary assessment and diagnostic services available to everyone thought to be suffering from dementia at the earliest opportunity Special focus on DS Care plans aimed at both patients and carers both now and in the future Continuous reviews Assessment of both practical and emotional needs of carers Training needs: identification and intervention based on symptoms including environment, activities and challenging behaviours Care plans tailored to residents traits Recognition of choices and rights Appropriate and accessible information on formats Multi agency and multidisciplinary modes of support Equal access to drugs and services Availability of high dependency services in future
Dodd, K. (2003)	<ul style="list-style-type: none"> Opinion paper on supporting people with DS and dementia 	<ul style="list-style-type: none"> Increased incidence of DS and dementia Less focus in literature on care and service issues General agreement on need for early diagnosis 	<ul style="list-style-type: none"> Need for early diagnosis More research/training on how best to support people (especially those with limited experience) Integration of psychosocial

		<ul style="list-style-type: none"> Increased understanding of care management but this is not always translated into reality 	<p>interventions into care</p> <ul style="list-style-type: none"> Adoption of Edinburgh principles by services Care managed by LD services
Earnshaw, K. & Donnelly, V. (2001)	<ul style="list-style-type: none"> Report on outcome of a health action zone scheme for people with DS using demographic data and a dementia screening pack 	<p>The following were found to be important throughout the project:</p> <ul style="list-style-type: none"> Assessment and diagnosis Development of the dementia screening instrument Dementia screening assessment tool has clarified assessment process Case study evidence Reviewing of assessments The care pathway Identification of training needs 	<ul style="list-style-type: none"> Publicise care pathway in day centres, residential and nursing homes Review of subjects every 6 months Staff and carers have awareness of how to access assessment process Training pack developed/training sessions developed Dementia working party developed – inter agency partnerships between service providers
Forbat, L. (2006)	<ul style="list-style-type: none"> Discussion of the views of key policy makers, implementers and practitioners' on aspects of 'Valuing People' considering gaps in provision for PLDs as they age 	<p>Interviewees identified hopes and fears for future policy as:</p> <ul style="list-style-type: none"> Training and developing competence, especially GPs, it particularly concentrating on the social model of disability and communication issues The rights of carers to make financial and health/social welfare decisions on behalf of relatives with LDs Improved access to daytime activities Guaranteed access to respite for family carers Development and use of widely flexible financial packages Housing policy aiming to combat exclusion and enable people to remain in their own homes with extra support 	<ul style="list-style-type: none"> Research asking similar questions as those posed in these interviews to service users Ensuring future policy and provision are based on the desires and needs of PLDs
Janicki, M. P. <i>et al.</i> (1996)	<ul style="list-style-type: none"> Report on AAMR/IASSID practice guidelines for assessment and care of PLDs with dementia and ATD 	<ul style="list-style-type: none"> The guidelines are suggestions not prescriptions. They suggest activities in three steps: <ol style="list-style-type: none"> Recognising changes Conducting assessments Instituting medical care and management It is recommended that support services and care management strategies should be designed to meet different needs at the various ages of the disease, including, early, mid and end stage 	<ul style="list-style-type: none"> Need for training in the normal processes of ageing and indicators of change signalling a dementing process Training needs to include materials, information, courses, policies, and should be offered to clinicians, workers, carers, peers and family Recommends training process to include: <ul style="list-style-type: none"> Understanding normal ageing, being aware of risk factors, recognising changes indicating the onset of dementia Dementia in PLDs, differentiability in symptoms Risk factors: age and family history, suggest periodic screening for

			<p>behavioural and longitudinal changes</p> <ul style="list-style-type: none"> • Early indicators – cognitive, health and functional
<p>McBrien, J. <i>et al.</i> (2005)</p>	<ul style="list-style-type: none"> • Report on progress of one LD service in setting up a register for adults with DS, conducting baseline assessments of cognitive and adaptive functioning before age 30, developing specialist skills in this area offering training to professionals, front line staff and carers and developing high quality co-ordination between services 	<ul style="list-style-type: none"> • Paper focuses mainly on screening programme • Sample screened (n=149) age range 18-77 varying levels of ID and place of residence • Re-screening presents particular challenges • 15% of those screened had 'probable ATD' • Refusal of screening is problematic 	<ul style="list-style-type: none"> • Training for carers is essential • Quality explanations of need for screening and help with gaining consent/assent • Assessment should cover both cognitive function and adaptive behaviour • Services need to consider a coordinated response to possible dementia' • Consideration of prescription of anti-Alzheimer's drugs to adults with DS and possible dementia
<p>McCarron, M. <i>et al.</i> (2005)</p>	<ul style="list-style-type: none"> • Report on a study investigating the amount of time formal caregivers spend addressing activities of day to day care activities for persons with DS with and without ATD 	<ul style="list-style-type: none"> • Significant difference in time spent care giving when AD is present in addition to LD, than when person has LD but not AD • Mid stage and end-stage AD did not impact on care giving time, but did impact on the nature of tasks • Clients with moderate LD had increased care giving time due to their previous higher rate of independence (compared to people with severe LD) 	<ul style="list-style-type: none"> • Different stages of AD demand different responses from caregivers e.g. supervision needs at mid stage and nursing care needs at end stage • If non specialist care settings are to continue to provide care they need to find ways of providing appropriate support through the different stages.
<p>Wilkinson, H. <i>et al.</i> (2005)</p>	<ul style="list-style-type: none"> • Report of 6 case studies discussing: • Attitudes and practices of staff working with people with LD and dementia • Supportive changes at organisational level • Knowledge and training needs of staff • Specific gaps in knowledge • Data collected from managers, direct care staff, fellow residents and relatives 	<ul style="list-style-type: none"> • Staff often feel guilt and a sense of failure when a resident is moved out • Staff under increasing stress as they try to cope without adequate support or specialist training (ad hoc access to training) • Many environments were disabling to clients but staff were unaware of this • Expressions of pain were wrongly viewed as 'challenging behaviour' 	<ul style="list-style-type: none"> • Specific training is required for staff supporting a resident who develops dementia • Staff should not be constrained in asking for help for fear that the resident will be moved out • Risk of staff 'burn out' should be addressed at organisational level • Waking night staff have an important role to play • Environments should be adapted appropriately

The majority of papers, which consider the needs of carers (table 11), focus on the educational and training needs of both informal and paid carers of people with learning disabilities who develop dementia. Janicki (1996) is perhaps the most specific, proposing that carers need training in the normal processes of ageing and the indicators of changes, which might signal a dementing process. He recommends that training should include: dementia in people with learning disabilities; differentiability in symptoms; and risk factors and suggests that training should include information, courses and policies and should be offered to workers, carers, peers and family. Wilkinson *et al.* (2005) discuss the need for education and training and also the need for extra staff when a client develops dementia. They recognise that staff may be reluctant to ask for help, fearing that the person with learning disabilities and dementia may be moved into, what they might consider to be, unsuitable accommodation, and suggest that services must address the risk of 'burn out' where staff attempt to manage the new challenges, which the development of dementia in a client poses.

3.2.5 Needs of peer group

As with the needs of carers, the needs of peer group members are closely intertwined with those of individuals with learning disabilities who develop dementia. In both families and supported housing situations the personalities and behaviours of all residents contribute to the wellbeing of the household, and when changes occur, these can have a profound affect on the quality of life of everyone in the group. Only two papers specifically addressed this issue (table 12). Lynggaard and Alexander (2004) report on successful group work with fellow residents in supported housing where two residents had developed dementia, and propose that it is essential to provide the peer group with accessible information and an environment where concerns and questions can be addressed. They found that the provision of such information and support had a lasting beneficial effect on the interaction between residents with and without dementia. Wilkinson *et al.* (2003) also report on group work with people with learning disabilities and provide a list of needs obtained from the group. These included awareness training on dementia, extra support for fellow residents and the individual with dementia, to enable that person to 'age in place', and support to visit and maintain contact if the individual with dementia has to move to a new care setting.

Authors	Study type	Main findings	Main recommendations
Lynggaard, H. &	<ul style="list-style-type: none"> • Discussion of group work with residents with 	<ul style="list-style-type: none"> • Discussions with residents found to be very helpful 	<ul style="list-style-type: none"> • Essential to provide accessible information

Alexander, N. (2004)	LD to explain the onset and effects of dementia on two fellow residents and to give the residents a forum to discuss the effects of living with others who develop dementia	<ul style="list-style-type: none"> Residents showed increased empathy and understanding and less impatience with their co-residents with dementia Interaction between residents without dementia and those with reported to have improved post interview Improvements continued after 6 months 	and an environment where concerns and questions can be addressed
Wilkinson, H. <i>et al.</i> (2003)	<ul style="list-style-type: none"> Report on a focus group study with people with learning disabilities on their knowledge of and attitude to dementia 	<p>Attitudes to growing older, relatively positive:</p> <ul style="list-style-type: none"> Most accepted they would need more help to carry out simple tasks Unpleasant physical changes that can occur with ageing Participants had a wealth of knowledge about changes that can occur when someone develops dementia Some participants expressed anxiety about the possibility that they would develop dementia 	<ul style="list-style-type: none"> To develop awareness raising and training on dementia To develop ways of sharing a diagnosis that are respectful and supportive To develop systems which enable people to 'age in place' To provide support to other service users who are living with a person with dementia Where people do need to move other users/residents should be encouraged and supported to give help and to maintain contact with the person in their new care setting

3.3 Models of Support

Papers which focus either mainly or in part on models of support for people with learning disabilities who develop dementia vary between the general and the specific. Bowman *et al.* (1996) discuss a support model developed for a single client with very particular needs, while Rosewarne (2001) describes the development of a support group involving a range of therapeutic approaches for people with LD and dementia. These included: person centred approaches, reminiscence work, cognitive work and informal reality orientation and the results were very positive, not only for the people with learning disabilities and dementia, but also for their motivating effect on other people (e.g. carers at the residential home).

Examples of more general models of support include that of Janicki *et al.* (2002) who describe a model for agency planning and service design aimed at providing a responsive 'dementia capable' support programme. Their ECEPS approach involves five components i.e. **E**arly screening and diagnostics, **C**linical supports, **E**nvironmental modifications, **P**rogramme adaptations and **S**pecialised care, all of which were developed in the generic

dementia care field and can be adapted and applied to the special situations in the field of dementia and learning disabilities. Earnshaw and Donnelly (2001) (table 11) also describe a more general model in their scheme developed by a multi disciplinary 'Health Action Zone' which included the development of a dementia screening pack and training in aspects of dementia within a multi cultural community. Janicki *et al.* (2002) describe the useful and relevant concepts of 'ageing in place', 'in place progression' and 'referral out', and these are also discussed in some detail by Kerr *et al.* (2006).

For those responsible for planning care for people with learning disabilities who develop dementia McCarron *et al.* (2002) suggest that the use of the CAS-ID offers a means of identifying and measuring care and resources and can assist with identifying appropriate interventions and models of care. McCarron (2005) (table 13) also proposes that different stages of AD demand different responses from caregivers e.g. supervision needs at mid stage and nursing care needs at end stage and argues that, if non specialist care settings are to continue to provide care they need to find ways of providing appropriate support through the different stages. Reilly (2005) (table 10) concurs with this and provides detailed guidelines for assessment of needs and care planning, arguing that care planning meetings should be held at least every six months due to the likelihood of ongoing changes.

Continuing their concern with caregiver response to the changing needs of people with dementia, McCarron and McCallion (2005) report on a review of the Stress and Coping Framework Model (Pearlin *et al.*, 1981 cited in McCarron and McCallion 2005) and modifications for its use to support research on the experiences of staff and carers of PLDs affected by dementia. Persaud and Jaycock (2001) focus their study more directly on the expressed needs of people with learning disabilities and dementia and describe the use of dementia care mapping (DCM) in learning disability services. This method is used to measure quality of care from the perspective of the recipient in generic dementia services, but Persaud and Jaycock aimed to explore how good practice in relation to quality of care initiatives in dementia care transpose into learning disability settings. They found the method had good potential but that some modifications were necessary. Their results highlighted some significant issues for care of people with learning disabilities and dementia.

Table 13: PAPERS ON MODELS OF SUPPORT			
Authors	Study type	Main findings	Recommendations
Adams, T. (2001)	<ul style="list-style-type: none"> • Proposal for multi-disciplinary pathway 	<ul style="list-style-type: none"> • The education and training pathway should include knowledge and practice relating to the bio psychosocial model, together with ethical and spiritual approaches • Psychosocial interventions 	

		<p>need to be met with at least an equal interest to that of care for the body, communication to be seen in political terms relating to empowerment.</p> <ul style="list-style-type: none"> • All therapeutic approaches to be based on reality orientation and validation therapy • Professional need to give up their claim to sole ownership of care and develop skills of leadership and inclusion that allow shared ownership of care • Multi-disciplinary practice developments • There should be a progression of skills development throughout the pathway appropriate to the level of engagement those taking the courses have with the people with dementia 	
Bowman, L. (1996)	<ul style="list-style-type: none"> • Discusses the treatment of a man with DS and dementia persistently running away from the residential facility where he had lived for 30+ years 	<ul style="list-style-type: none"> • Individual treatment plan designed and initiated to eliminate problem behaviour • Second treatment plan instituted after difficulties emerged with plan 1 • Second plan eliminated behaviour, which re-emerged 6 months later and 4 months after treatment programme had been stopped. • Response priming i.e. allowing dementia patients to 'generate' information (e.g. when patient asks for something he is asked what he must do to earn the asked for reward) may allow them to remember more 	<ul style="list-style-type: none"> • Reinforcement priming can be useful in focusing attention of person with dementia on required task • Ability to relearn may be enhanced if the same method originally used to teach a behaviour is employed • Future research could determine whether frequent response priming could prevent re-emergence of problems which have re occurred
Gillard, J. <i>et al.</i> (2005)	<ul style="list-style-type: none"> • Draws on a research project considering the needs of 2 groups of people with dementia: younger people (age<65) and minority ethnic groups 	<ul style="list-style-type: none"> • A social model of disability theory makes us confront ways in which we discriminate against people with dementia and marginalise people with dementia in the way services are designed and delivered • Examples of good practice where services took a holistic view of users: <ul style="list-style-type: none"> • Services allowed people to contribute to daily activities • Consulting with people with dementia as users of the service and gaining feedback on suggested 	<ul style="list-style-type: none"> • Until the sharing of the diagnosis is seen as good practice and is managed routinely in clinical care it will be difficult to rigorously apply the social model of disability to dementia care • To continue trying to situate our understanding of dementia care within the social model

		<p>changes /improvements</p> <ul style="list-style-type: none"> • Found at as much as possible about the person and used to inform care plan • There is a growing body of evidence that people with dementia want to be told what is wrong with them and want to be kept up to date with their progress 	
Janicki, M. P. <i>et al.</i> (2002)	<ul style="list-style-type: none"> • Report of the outcome of a survey of group homes for people with LD and dementia • Explores the onset, duration and effects of dementia, discusses the impact of these on planning community care for adults with LD • Examination of 2 models: 'Ageing in place' and 'In place progression • Offers a model (ECEPS) for responding to dementia 	<ul style="list-style-type: none"> • Agencies can adapt existing services to become 'dementia capable' housing • A range of rather subjective factors influence agency decision making • Very little evidence in practice of 'dementia capable' housing • ECEPS approach emerged from the study aimed at providing a responsive 'dementia capable' programme • Involves 5 components <ol style="list-style-type: none"> 1. Early screening and diagnostics 2. Clinical supports 3. Environmental modifications 4. Programme adaptations 5. Specialised care 	<ul style="list-style-type: none"> • Expanded research agenda to examine 'Ageing in place' and 'referral out' which aim to promote higher quality of life and maintain dignity in the least restrictive community settings
Kerr, D. <i>et al.</i> (2006)	<ul style="list-style-type: none"> • Report of study commissioned by Joseph Rowntree Foundation 'Home for Good' (Wilkinson <i>et al.</i>, 2004) 	<p>Describes 3 models of support:</p> <ul style="list-style-type: none"> • Ageing in place – Remain in own home with appropriate support and adaptations if necessary • In place progression – Environment developed to become increasingly specialised to provide care (not usually in present accommodation) within learning disability service • Referral out – Move to long term (usually nursing) facility usually outside learning disability service. 	<p>Areas which need greater attention:</p> <ul style="list-style-type: none"> • Better training and support for direct care staff • Provision of waking night staff • Improvements to built environment • Improved diagnostic pathways • Services that meet needs of people 'referred out' • Additional requirement to develop 'outreach model' incorporating: <ul style="list-style-type: none"> • Extra support for residents without dementia • Palliative care services • Other professional expertise e.g. speech therapy • Staff to give advice and support on dementia • Quality dementia-specific respite care

<p>McCarron, M. (1999)</p>	<ul style="list-style-type: none"> Opinion paper concerning issues in caring for people with DS and AD 	<ul style="list-style-type: none"> Increased prevalence of AD has major implications for service development Diagnosis presents many challenges but needs to be accurate and swift in order to develop service responses A shared vision of care is important for consistency Well being of clients can be promoted by interventions and attitudes that focus on the positive Specific interventions are advocated but it is the attitude that shapes their delivery which is seen as key 	<p>Overarching recommendation for staff to encourage clients to be empowered.</p> <p>Specifically:</p> <ul style="list-style-type: none"> Training for staff and families in recognising common health problems Challenge staff to recognise unique ways that people adapt to meet challenges they face as condition develops Specific interventions suggested include making meal times a therapeutic event; sensitive handling of reality orientation; validation techniques and individually tailored activity programmes
<p>McCarron, M. <i>et al.</i> (2002)</p>	<ul style="list-style-type: none"> Report on testing of an amended care giving survey the 'Caregiver Activity Survey – Intellectual Disability' (CAS-ID) for use by professional caregivers of people with DS and ATD 	<ul style="list-style-type: none"> Preliminary evidence offered for the validity and reliability of CAS-ID Instrument offers a means of identifying and measuring care and resources required as this population experience symptoms of dementia Use of instrument can help to identify appropriate interventions and models of care 	<ul style="list-style-type: none"> Information gained as a result of using this instrument may assist health care professionals in planning support and services to address the care challenges evident at different stages of the disease process Longitudinal use of instrument may contribute to overall understanding of clinical course and nature of progression of ATD in persons with DS
<p>McCarron, M. and McCallion P. (2005)</p>	<ul style="list-style-type: none"> Report on review of Stress and Coping Framework Model (Pearlin <i>et al.</i>, 1981) and modifications for its use to support research on the experiences of staff carers of PLDs affected by dementia 	<p>Considers how Pearlin's model (Pearlin <i>et al.</i>, 1999) can be adapted to provide a more theoretical underpinning to how staff stress/coping is addressed. Components include:</p> <ul style="list-style-type: none"> Background and context (characteristics of caregiver and caring environment) Primary / secondary stressors e.g. cognitive status, conflict, care-giving mastery Mediating factors (coping, support, environment) Outcomes (physical / mental health consequences) 	<ul style="list-style-type: none"> Recommends further development and testing of the model
<p>McQuillan, S. <i>et al.</i> (2003)</p>	<ul style="list-style-type: none"> Overview of current research 	<ul style="list-style-type: none"> A comprehensive assessment should include: 	<ul style="list-style-type: none"> Individuals with DS should have a

	concerning DS and AD	<ol style="list-style-type: none"> 1. Medical assessment 2. Behavioural assessment 3. Adaptive assessment] 4. Cognitive assessment 5. Background history 6. Psychosocial/psychiatric assessment <ul style="list-style-type: none"> • The recommended approach is to establish a baseline level of functioning then repeat to establish if decline is occurring • Emphasis on maintaining present level of skills rather than developing new skills • Individuals are best cared for by services with specific LD expertise 	<p>baseline level of functioning assessed before the age of 30, this should be repeated every 12-18 months</p> <ul style="list-style-type: none"> • Training is required for GPs, carers, staff and professionals in LD services to raise awareness and recognition of signs and symptoms of AD • Services need to be developed to meet the current lack of appropriate residential and day services for people with DS and AD • Multi-disciplinary care planning and coordination between and within agencies is essential • Assessment tools need to be standardised and refined to aid early diagnosis and detection
Persaud, M. & Jaycock, S. (2001)	<ul style="list-style-type: none"> • Observation of behaviour of staff and LD residents using data collection tool designed for people with dementia • 32 hours of observation carried out, each observation being conducted by 2 observers • Observations undertaken in 3 residential areas 	<p>Effectiveness of method:</p> <ul style="list-style-type: none"> • Most codes could be used but some problems with interpretation due to extended range of behaviours exhibited by some people with LDs • Also difficulties due to different connotations of behaviour in LD settings compared with dementia care settings <p>Efficiency of method:</p> <ul style="list-style-type: none"> • Facilitated collection of 'rich and detailed' data, which was useful in providing 'hard data' for staff • Results indicated a need to change cultural values of care and staff were surprised by findings • Overall efficiency supported in LD settings but not in relation to scoring of well being • There is a gap between philosophy of care and observed practice 	<ul style="list-style-type: none"> • Recommend use of DCM in LD settings as a tool to evaluate care delivery
Rosewarne, M. (2001)	Description of the development of a support group involving a range of therapeutic	<p>Within one year of being in the therapy group:</p> <ul style="list-style-type: none"> • Visually aided weekly timetable developed and used by participant and 	<p>Recommendations are based on the author's personal experience:</p> <ul style="list-style-type: none"> • Psychotherapeutic approaches employed

	<p>approaches for people with LD and dementia. These included:</p> <ul style="list-style-type: none"> • Person centred approaches • Reminiscence work • Cognitive work • Informal reality orientation • Wide variety of equipment 	<p>support staff combined with informal reality orientation has resulted in dramatic improvements in orientation in time and place</p> <ul style="list-style-type: none"> • Ability to learn new concepts and information • No deterioration in verbal communication • Maintenance of levels of wellbeing • The positive effect of the group has had a motivating effect on other people (e.g. carers at the residential home) 	<p>with people from the wider population who develop dementia are effective with people with LDs too, but differences within the population and between individuals must be considered and techniques modified accordingly</p> <ul style="list-style-type: none"> • LD services need to develop both knowledge and skills in this field, and approaches developed which can be confidently employed • Stronger links should be developed with specialised services to enable shared practise of expertise • Research is imperative to assess the effectiveness of these approaches and improve future service provision
<p>Soliman, A. & Hawkins, D. (1998)</p>	<ul style="list-style-type: none"> • Literature review examining the needs of family and professional carers for people with DS and AD 	<ul style="list-style-type: none"> • There needs to be adequate service provision for an increasing number of people with DS who develop AD at a relatively early age • Nurses in both dementia care and LD have a role to play in the care of people with DS and AD with community nurses caring for clients with LD and dementia and specialists acting as consultants, providing advice, education and training • There is very little relevant information for family carers , they may be aware of minor changes in their relative without being aware of their significance 	<ul style="list-style-type: none"> • Carers and family members need accurate information which explains the difference between normal and pathological signs of ageing • There is a need for a screening programme with identified people being responsible • There should be an individualised package of care with a clearly identified key worker

3.4 Services

Less than 15% (n=25) of the papers included in this literature review were relevant to the question 'Which service sectors are taking the lead in the development and delivery of services for people with learning disabilities who develop dementia'. The general consensus was that Learning Disability Services should be the main provider. Only one study (Moss and Patel, 1997) (table 7) suggested that the needs of people with learning

disabilities who develop dementia can be adequately dealt with by generic services specialising in dementia, although others agree with Watchman (2003) (table 9) that people with learning disabilities and dementia should have the same access to dementia services as those without learning disabilities.

Kerr *et al.* (2006) (table 13) describing the 3 models of care i.e. 'Ageing in place', 'In place progression' and 'Referral out' propose that 'Ageing in place' is the ideal and argue that clients are usually 'referred out' because their current placement is not 'dementia ready'. They suggest that more training for staff and support for fellow residents is needed when a client develops dementia. They also argue the need for waking night staff due to dementia behaviour and the development of an 'outreach' service to enable people with learning disabilities who develop dementia to remain in their own homes. Several studies agree that there may be a progression from social care to health care for people in the terminal stages of dementia with Cosgrave *et al.* (2000) (table 7) proposing that 'Specialised hospice type units appear to be the most suitable accommodation for subjects with end stage dementia'.

Adams (2001) (table 13), although not dealing specifically with the needs of people with learning disabilities and dementia, describes proposals for a multi-disciplinary education and training pathway for dementia care. He argues that:

Professionals need to give up their claim to sole ownership of care and develop skills for leadership and inclusion that allow shared ownership of care.

Adams is not alone in this suggestion. Thompson (2002) proposes that:

Management [of dementia] depends on good collaboration between Primary Care Trusts, Community Teams for People with Learning Disabilities, and carers, and the coupling of expertise in gerontology and learning disability.

Sixteen of the twenty five papers in this section argue for 'multi agency and multi-disciplinary modes of support' (Davies, *et al.*, 2002) (table 11) and the majority concur with Holland (2000) that health and social services need to develop joint strategies for ensuring that, as dementia progresses, the changing needs of the affected persons can be met.

Hatzidimitriadou and Milne (2005) present evidence about the nature, extent, and quality of policy and services and explore future directions. They make many recommendations including:

A partnership between LD agencies and older people services with help from Mental Health trusts and Housing Agencies, a coherent, effective and well-funded service

planning system, access to flexible care for users and carers when it is needed and the development of dedicated provision.

Table 14: PAPERS ON SERVICE RESPONSIBILITIES FOR PEOPLE WITH LEARNING DISABILITIES AND DEMENTIA			
Author	Type of study	Main findings	Main recommendations
Dodd, K. (2003)	<ul style="list-style-type: none"> Opinion paper on supporting people with DS and dementia 	<ul style="list-style-type: none"> Increased incidence of DS and dementia Less focus in literature on care and service issues General agreement on need for early diagnosis Increased understanding of care management but this is not always translated into reality 	<ul style="list-style-type: none"> Need for early diagnosis More research / training on how best to support people (especially those with limited experience) Integration of psychosocial interventions into care Adoption of Edinburgh principles by services Care managed by LD services
Forbat, L. (2006)	<ul style="list-style-type: none"> Discussion of the views of 'key policy makers, implementers and practitioners' on aspects of 'Valuing People' considering gaps in provision for PLDs as they age 	<p>Interviewees identified hopes and fears for future policy as :</p> <ul style="list-style-type: none"> Training and developing competence, especially GPs, it particularly concentrating on the social model of disability and communication issues The rights of carers to make financial and health/social welfare decisions on behalf of relatives with LDs Improved access to daytime activities Guaranteed access to respite for family carers Development and use of widely flexible financial packages Housing policy aiming to combat exclusion and enable people to remain in their own homes with extra support 	<ul style="list-style-type: none"> Research asking similar questions as those posed in these interviews to service users Ensuring future policy and provision are based on the desires and needs of PLDs
Forbat, L. & Pekala-Service K. (2005)	<ul style="list-style-type: none"> Literature review on aspects of end-of-life care for people with LD and dementia 	<ul style="list-style-type: none"> Meanings people give to situations are shaped by a range of factors such as relationships, beliefs and attitudes Meaning is thus contextual Use of the hierarchy model within the 'Coordinated Management of Meaning' approach (CMM) allows reflection on the range of systems which impact upon care provision for PLDs with dementia Such systems include the belief systems of relatives, cultural factors and legislation 	<ul style="list-style-type: none"> Policy should be cognisant of contextual factors and these should be made explicit to allow for critical appraisal of how issues of context influence practice That practitioners consider a range of viewpoints and use these to work more creatively

		<ul style="list-style-type: none"> • Analysis allows for identification of not just how a situation is viewed but also why beliefs are held • This allows for levels of identification at which change might occur 	
Hatzidimitriadou, E. & Milne, A. (2005)	<ul style="list-style-type: none"> • Opinion paper on meeting needs of older people with LDs in the UK 	<p>The article draws together evidence about the nature, extent and quality of policy and services and explores future directions:</p> <ul style="list-style-type: none"> • Older people with LD are at greater risk of developing serious medical conditions and a range of physical and psychiatric conditions • Older carers are at risk of becoming physically ill • Different policy developments are discussed in • The National Service Framework for Older people • The Carers and Disabled Children's act 2000, • Learning Disability Boards • The majority of studies on service provision are descriptive rather than systematic • Services respond reactively rather than proactively to the changing needs of older people 	<p>Essential pre-requisites for effective service development:</p> <ul style="list-style-type: none"> • An established strategic framework for planning to which all key stake-holders are committed and contributing • A partnership between LD agencies and older people services with help from mental health trusts and housing agencies • A service plan for older people with LD and their carers underpinned by dedicated funds • Evidence of the existing extent and nature of service provision • Flexibility of commissioning • recognition of workforce and training issues • Despite some evidence of positive development in this area, much more remains to be done to ensure: <ul style="list-style-type: none"> • Continuity of care across the life course, particularly in the later stages • A coherent, effective and well-funded service planning system • Access to flexible care for users and carers when it is needed • The development of dedicated provision
Holland, A. J. (2000)	<ul style="list-style-type: none"> • Literature review aimed at finding out how ageing affects people with LDs 	<ul style="list-style-type: none"> • There is a convergence in later life between people with LDs and those without, owing to reduced life expectancy of people with more severe disabilities • People with DS have 	<ul style="list-style-type: none"> • Health and social services need to develop joint strategies for ensuring the changing needs of people with LDs can be met

		particular risks of age related problems relatively early in life	<ul style="list-style-type: none"> • Further study required to investigate influences on age related morbidity and mortality, particularly in those with severe LDs • Early detection and treatment of physical and mental health problems in people with LDs are key responsibilities for primary and secondary health services
Kalsy, S. <i>et al.</i> (2005)	<ul style="list-style-type: none"> • Description and assessment of proactive screening for dementia in older adults with LD • Appraisal of the dedicated clinical psychology service strategy 	<ul style="list-style-type: none"> • Dedicated psychology services for dementia assessment can be effective in offering a defined and valuable psychological response to increasing presentation of dementia-associated behaviours among people with LD 	<ul style="list-style-type: none"> • Should get carers to contribute to assessment and intervention process, so as to ensure responsive and respectful case management for person with LD and dementia • A proactive psychology screening and multi-modal intervention model can have as its goal, the enhancement of quality of life for people with LD as they age • A dedicated service combined with interdisciplinary and cross agency working can emphasize a commitment to the core principles of choice, partnership, dignity and respect for people with DS and other forms of LD in later life
McCallion, P. <i>et al.</i> (2005)	<ul style="list-style-type: none"> • Pilot study comparing matched samples from foster family care providers and staff caregivers in other settings on the subjective and objective burden of care for people with LD and dementia 	<ul style="list-style-type: none"> • No differences were found in caregiver subjective burden between the 2 groups • Staff in group homes spent more time addressing behavioural concerns than foster families • Group home staff spent more time on bathing, eating and nursing care than foster family carers • Foster family carers spent more time on housekeeping and related activities 	<ul style="list-style-type: none"> • Need to investigate transitions from foster family care situations when persons present with dementia • May be possible to increase levels of support to keep such persons in the foster care situation • Policy makers, planners and services administrators need to be thinking about the mix of services and supports likely to sustain people with

			LD and AD in foster family care homes
McCarron, M. & Lawlor, B. A. (2003)	<ul style="list-style-type: none"> Irish data on population with LD and ATD, reviews generic and LD specific literature, considers policy context and proposes a model for the development of multidisciplinary specialist teams within LD through mobile LD/dementia clinics 	<p>Proposes development of a dementia service for older people with LD based on :</p> <ul style="list-style-type: none"> Diagnosis and assessment of ATD Multi disciplinary assessment and clinical support Environmental modification Education and training 	<ul style="list-style-type: none"> Increase awareness amongst professionals and family carers of dementia / cognitive decline Develop training and education on dementia management Develop accurate information Develop continuing care within PCP Use family centred planning
McKenzie, K. <i>et al.</i> (2002)	<ul style="list-style-type: none"> Report of results of a short questionnaire on dementia knowledge 	<ul style="list-style-type: none"> No significant differences were found between the 2 groups in terms of gender or years of experience No significant difference between the 2 groups in relation to describing AD No significant difference between the 2 groups in relation to ability to identify factors which might mimic the effects of AD Group A had greater total knowledge scores than group B Around half the total sample was aware that AD was a form of dementia Similar proportions of each group felt that people with DS experienced more health problems than the general population Group A could identify significantly more health problems 	<ul style="list-style-type: none"> An obvious role for the provision of training for staff who support clients with DS as well as the development of joint policies and procedures between health services, social work and non statutory agencies
McQuillan, S. <i>et al.</i> (2003)	<ul style="list-style-type: none"> Overview of current research concerning DS and AD 	<ul style="list-style-type: none"> A comprehensive assessment should include: <ol style="list-style-type: none"> 1) Medical assessment 2) Behavioural assessment 3) Adaptive assessment] 4) Cognitive assessment 5) Background history 6) Psychosocial/psychiatric assessment The recommended approach is to establish a baseline level of functioning then repeat to establish if decline is occurring Emphasis on maintaining present level of skills rather than developing new skills Medical management increasingly important as disease progresses 	<ul style="list-style-type: none"> Individuals with DS should have a baseline level of functioning assessed before the age of 30, this should be repeated every 12-18 months Training is required for GPs, carers, staff and professionals in LD services to raise awareness and recognition of signs and symptoms of AD Services need to be developed to meet the current lack of appropriate residential and day services for

		<ul style="list-style-type: none"> Individuals are best cared for by services with specific expertise in learning disabilities 	<p>people with DS and AD</p> <ul style="list-style-type: none"> Multi-disciplinary care planning and coordination between and within agencies is essential Assessment tools need to be standardised and refined to aid early diagnosis and detection
Soliman, A. & Hawkins, D. (1998)	<ul style="list-style-type: none"> Literature review examining the needs of family and professional carers for people with DS and AD 	<ul style="list-style-type: none"> There needs to be adequate service provision for an increasing number of people with DS who develop AD at a relatively early age Nurses in both dementia care and LD have a role to play in the care of people with DS and AD with community nurses caring for clients with LD and dementia and specialists acting as consultants, providing advice, education and training There is very little relevant information for family carers, they may be aware of minor changes in their relative without being aware of their significance 	<ul style="list-style-type: none"> Carers and family members need accurate information which explains the difference between normal and pathological signs of ageing There is a need for a screening programme with identified people being responsible There should be an individualised package of care with a clearly identified key worker
Thompson, S. B. N. (2002)	<ul style="list-style-type: none"> Literature review providing advice on diagnosis and management of dementia in older people with DS 	<ul style="list-style-type: none"> Prevalence rates exceeded the number of people with observed deterioration before death (may be due to poor identification of decline). Assessment dependent on gaining reliable history of individual's abilities Risk of misdiagnosis due to other causes of decline (which may also be unexplored) Progression similar to that in the general population 	<ul style="list-style-type: none"> Management depends on good collaboration between PCTs, CTLDs and carers and the coupling of expertise in gerontology and learning disability
Wade, R. <i>et al.</i> (2003)	<ul style="list-style-type: none"> Review of screening tools for assessing dementia in people with LD: <ul style="list-style-type: none"> Dementia Baseline Screening Process Dementia Questionnaire for the Mentally Retarded Adaptive Behaviour Scale for Residents in the Community 	<ul style="list-style-type: none"> Staff needed better understanding of the nature and course of dementia, associated behaviour and how to improve individual's quality of life Structured assessment enabled staff to gather routine baseline data on the target group of clients to enable more accurate monitoring by the service of any subsequent deterioration This aspect of the service has been developed and maintained within the existing hours of an assistant clinical 	<ul style="list-style-type: none"> A Dementia Baseline Screening Service would be a useful development in either clinical psychology LD services or multi disciplinary LD teams

		psychologist, highlighting that the approach is achievable within limited resources <ul style="list-style-type: none"> • Funding sources to develop and extend this role are being sought 	
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4. CONCLUSIONS

In reviewing the papers for this study, it was not always easy to assign papers to a particular category and some papers will thus appear in more than one table. Many papers provided a great deal of detail that is difficult to summarise within the tables and readers are advised to use the tables as a resource and to follow up their interests by reading the original studies where appropriate.

Most studies have some limitations and the usefulness of many of the papers reviewed here was limited by their small sample size. In many cases, the sample studied was non representative of the total population of people with learning disabilities and dementia. A few studies had methodological limits and many included only people with mild learning disabilities or, at the other end of the scale, were restricted by the poor communication skills and severity of the learning disability of those studied. A number of the studies relating to the assessment and diagnosis of dementia were limited by the lack of consistent diagnostic criteria for Alzheimer's dementia.

Despite these limitations much useful information was gained from this review. Better awareness and detection of early signs and symptoms of dementia depends on regular medical and psychological assessment starting at an age when there are unlikely to be symptoms of dementia. There is no single diagnostic tool, which will be suitable for every person with learning disabilities, but there is a multitude of such tools and advice is available as to which tool is most suitable for the different client groups.

The overwhelming need of people with learning disabilities who develop dementia is for familiar services which can (and will) be adapted to meet their changing needs. The needs of carers are closely intertwined with those of clients and meeting the needs of the latter e.g. for staff training and increased staff numbers, will certainly have beneficial effects on the person with learning disabilities and dementia. Of the models of support presented in the literature the models 'ageing in place', 'in place progression' and 'referral out' (Janicki, *et al.*, 2002) offer guidelines for the care of people with learning disabilities and dementia throughout the course of their disease, the ideal being that individuals can 'age in place' with appropriate support.

It is unlikely that a single service would take total responsibility for people with learning disabilities and dementia. There is a definite consensus that learning disability services should be heavily involved and that the preferred option is a sharing of responsibility between social services, health and specialist dementia services, including those on offer to the generic population.

5. FUTURE RESEARCH

Many of the papers reviewed suggested further research was necessary and larger sample sizes spread over a much broader area and including people with learning disabilities and dementia living in a variety of circumstances were suggested in many studies. Longitudinal studies of the signs and symptoms of dementia were proposed in many of the papers reviewed and these were felt to be of great importance if baseline information i.e. information gathered before the development of dementia, could be available for purposes of comparison. A country wide survey of dementia services for people with learning disabilities and dementia would definitely be a useful tool in the management of this population.

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