Ageing and Intellectual Disabilities

A Study into Clinical Psychologists' Experiences of Meeting the Needs of Ageing People with Intellectual Disabilities

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Overview

Research into ageing with intellectual disabilities (ID) is relatively new as ID has primarily been viewed as a paediatric condition. With the discovery that people with Down's syndrome are at higher risk of developing dementia of the Alzheimer's type, there has been an increased focus on ageing with ID. Much of the research, however, takes a biomedical stance and focuses on assessment of dementia in this cohort and there remains a paucity of research into service provision and care management models as well as experiential issues of ageing with ID. Without this research, people with ID may encounter fragmented and poorly resourced services as they age, with their increased health and social care needs remaining unmet.

The first section of this thesis, a review paper, describes and critiques the existing research into ageing and intellectual disabilities and current service provision including assessment and care management models. The paper also explores the service provision for older adults in the general population to see whether similar dilemmas and issues encountered by ID services occur for older adult services. The review examines in detail one particular model of assessment and intervention for dementia, namely the memory clinic model. The last part of the paper examines clinical and ethical issues of dementia practice, primarily the disclosure of a dementia diagnosis and concludes by asking whether clinical psychologists experience similar dilemmas when discussing dementia with people with ID.

The second section, an empirical paper, presents analysis of responses from a questionnaire sent nationally to clinical psychologists specialising in ID. This survey captured a snapshot of current practice in meeting the assessment and intervention
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Review Paper

The theory and practice of meeting the needs of ageing people with intellectual disabilities
Abstract

Over the next 20 years the number of people living to over 65 is expected to rise by 16%, with the greatest proportional increase being in those over 80 (Audit Commission, 2000). These current demographic trends are challenging those responsible for planning the future pattern of health and social care as well as its financial sustainability. This trend is not exclusive to the general population with evidence of these demographic changes being mirrored in the intellectual disabilities population. Improvements in standard of living and access to medical treatments have resulted in better health and enhanced longevity for people with intellectual disabilities (PWID) (Hatzidimitriadou & Milne, 2005).

The ramifications of these statistics are increasing challenges for policymakers and services providers to meet the changing health and social care needs of this cohort. This review paper will focus on the issues facing professionals when attempting to meet the needs of this ageing intellectual disability cohort such as assessing dementia as well as explore how services are meeting the needs of older adults in the general population for example, memory clinics and person centred dementia care. Finally an area of older adult work that has been explored in depth in the older adult literature, namely the disclosure of a dementia diagnosis will be discussed.

The paper concludes that both ID and older adult services have independently advanced the knowledge on neuropathological and psychosocial dimensions of dementia yet have failed to engage in cross cutting dialogue to share their research findings, impeding the development of a universal approach to ageing.
Ageing and Intellectual Disabilities

1. Ageing with Intellectual Disabilities

1.1 Down’s Syndrome and dementia

Ageing in the Intellectual Disability (ID) population was not a research priority for scientists, clinicians or policy analysts until as recently as 20 years ago, as ID was seen primarily as a paediatric diagnosis, with an emphasis on its developmental course during the childhood period and early adulthood (Seltzer, Heller & Krauss, 2004). However, it is now well recognized that the impact of intellectual disabilities is life long and that the ageing process is as relevant to this population as it is to society at large.

The interest in the ageing process of PWID was first promulgated due to the discovery of the high risk of Dementia of the Alzheimer Type (DAT) in people with Down’s syndrome (Zigman et al., 2004). Although the focus is now broadening to include ageing of people without Down’s syndrome (Zigman et al., 2004), Prader Willi Syndrome (Dykens, 2004) and Fragile X syndrome (Jacquemont et al., 2004), the majority of research interest remains focused on people with Down’s syndrome, particularly the assessment and diagnosis of DAT, rather than guidance on service provision and care management (Jokinen, 2005).

The neuropathology of DAT is characterised by the presence of two distinct types of lesions, senile plaques and neurofibrillary tangles (Percy, 1999). The amyloid beta protein (Aβ) is a breakdown product of Amyloid Precursor Protein (APP) and in normal function Aβ is soluble and is deposited outside the cell and then dispersed.

1 The term Intellectual Disabilities will be used throughout this review rather than learning disabilities, to reflect the international usage of the term in ID research, policy and practice.
When Aβ comes into contact with abnormally phosphorylated tau protein it becomes insoluble and the cell can no longer deposit it. This insoluble Aβ forms deposits that became dense neuritic plaques over time, trapping other plaque components. This gradual process manifests with cell death and contributes to cerebral atrophy. Neurofibrillary tangles result from the phosphate accumulation on the tau protein and leads to paired helical filaments. These filaments accumulate on the neurone and build up with eventual disruption of neuronal function (Percy, 1999).

Virtually all adults with Down’s syndrome over 35 to 40 years who have been autopsied have the key neuropathological changes characteristic of DAT (Wisniewski, Wisniewski & Wen, 1985) and approximately 50-60% of these individuals may develop DAT by the time they reach 60-70 years of age (Zigman, Schupf, Haveman & Silverman, 1997). The triplication of chromosome 21, a characteristic Down’s syndrome phenotype, is particularly significant in DAT neuropathology as the gene for APP is located on chromosome 21. The triplication of chromosome 21 and the resultant over expression of APP has therefore been linked to the increased risk of neuritic plaque formation in individuals with Down’s syndrome (Schupf, 2002).

Although it has been established that people with Down’s syndrome have high levels of Aβ deposition by the age of 40 years and the presence of early dementia neuropathology, the average age of onset of clinical dementia is 55 years and varies widely. Schupf (2002) argues that other risk factors must exist in order to account for this wide variation. She reviewed studies exploring the possible factors that influence the formation and deposition of Aβ, including atypical karyotypes, genetic susceptibility,
gender and oestrogen deficiency and individual differences in Aβ peptide levels. Schupf (2002) concluded that apolipoprotein (APOE) e4 allele, oestrogen deficiency and high levels of Aβ1-42 peptide are associated with earlier onset dementia while atypical karyotypes and the APOE e2 allele are associated with reduced mortality and reduced risk of dementia. Schupf (2002) concluded, however, that studies were limited in their findings due to methodological constraints such as small sample sizes. These studies were often not controlled for potential confounders and modifiers such as age, gender and level of intellectual disability and that most studies use prevalence rather than incidence cases, which may mask the effect of risk factors for disease onset due to difference in survival rates.

Other factors that have been implicated in attempting to explain the variation in clinical onset, are biological processes such as oxidative damage (De Hann, Cristiano, Iannello & Kola, 1997, as cited Bush & Beail, 2004) and pre-existing differences in intellectual impairment, known as the cognitive reserve hypothesis. This cognitive reserve model predicts that individuals who already have a reduced neuronal complement in a particular area of the brain would have increased susceptibility to even small neuropathological progression, for example people with Down’s syndrome have hypoplasia of frontal lobes and maybe susceptible (Holland, Hon, Huppert, Stevens & Watson, 1998). It is argued that the degree of pre-existing cognitive impairment would be expected to be associated with an earlier onset of DAT and a faster rate of deterioration. Also those people with severe and profound intellectual disabilities would be more vulnerable to the onset of DAT then those with mild intellectual disabilities.
Holland, Hon, Huppert & Stevens (2000) postulated that the earliest features of DAT give rise to a similar picture found in frontal dementia, namely behavioural and personality changes. Holland et al., (2000) argued that if these cognitive and behavioural changes could be monitored longitudinally and found to precede the emergence of sufficient clinical change to meet diagnostic criteria for DAT for some years, then one could account for this mismatch in observed neuropathological change and clinical presentation. Utilising a cohort from a previous longitudinal prevalence study (Holland, Hon, Huppert, Stevens & Watson, 1998) they tracked cognitive and behavioural change, using a modified Cambridge Examination for Mental Disorders of the Elderly (CAMDEX) informant interview and neuropsychological assessments, over three time points yielding both prevalence and incidence data. They found where change had occurred it was predominantly in the area of behaviour and personality and where dementia had progressed the diagnosis had shifted from frontal like dementia to DAT and the numbers of people with Down’s syndrome presenting with frontal like dementia were higher in the younger participants, than the older group where more incidences of DAT were found. The researchers concluded that the frontal lobes are compromised early in the course of the of the DAT neuropathology and further research needs to be conducted into frontal lobe functioning of this cohort. Holland et al., (2000) acknowledged methodological limitations to their study, namely the sample size was small (n=68) and the assessment tools, such as the modified CAMDEX may not have had validity for diagnosis of dementia in this cohort. However, recent research has since found the modified CAMDEX informant interview to be valid and reliable for the diagnosis of dementia (Ball, Holland, Huppert, Treppner, Watson & Hon, 2004).
With regards to PWID without Down’s syndrome, the cognitive reserve hypothesis has been challenged by a well designed study by Zigman et al., (2004). They found lower than expected, or even equivalent, rates of DAT among adults with intellectual disabilities compared to the general population. They comprehensively assessed adults with ID but without Down’s Syndrome over the age of 65 at 18 month intervals, using assessments of adaptive and cognitive functioning, blood tests to test for genetic markers as well as neurological examinations. The authors conceded that their small sample (n=126) may not be representative although their use of a longitudinal rather than cross sectional design was a strength of the study.

The cognitive reserve model appears to be useful in explaining the mismatch between evidence of neuropathology of dementia and the clinical onset in people with Down’s syndrome. It is less useful and has been challenged by studies, for PWID but without Down’s syndrome. It is evident that further research is needed to investigate the cognitive reserve hypothesis, particularly neuropsychological studies to establish normal and impaired frontal lobe functioning in PWID. This work has begun with a recent study by Rowe, Lavender & Turk (2006) who investigated executive functioning in adults with Down’s syndrome. They found the Down’s syndrome group performed at a significantly lower level on a number of executive function tests when compared to a group of adults with ID but without Down’s syndrome.

1.2 Methodological Issues

Although theories are emerging to explain the course and progression of DAT in people with and without ID, research is hampered by ongoing methodological issues,
particularly with prevalence and incidence studies. Bush & Beail (2004), in their review, identified major methodological limitations to many of the published studies and concluded that these design problems were contributing to the variability of the findings. For example, cohort bias in cross-sectional designs compound any reported differences and instead may account for changing standards and opportunities for education in different age cohorts, medical conditions, and the individual’s place of residence with varying opportunities for intellectual stimulation and activity. Many early studies sourced their sample from long stay institutions whereas in recent years, with the move to community living, PWID have had increased options for activity and learning thus cross sections may perform differently. Population-based longitudinal studies provide opportunities to overcome some of these biases that are inherent in cross sectional designs, where cohorts of different age spans are followed over a period of years (Carr, 2003; Holland et al., 2000).

Another drawback to many studies is the diagnostic criteria for DAT. Differential diagnosis can bring difficulties to even the most rigorously designed study as consensus has yet to be reached on diagnostic criteria for DAT as well as other dementias such as vascular dementia, in PWID with and without Down’s syndrome. These diagnostic differences can lead to false positives being reported. For example, the well designed study using both DSM-IV and ICD-10 diagnostic criteria by Holland et al., (2000) found from a group of 68 who met criteria for dementia at first assessment, 2 had ‘less severe’ diagnoses 18 months later, raising doubts about earlier diagnosis.
In addition a lack of reliable and valid assessment tools continues to hinder studies, particularly as many assessment tools are insufficiently sensitive to detect decline. The absence of appropriate norms for PWID results in floor effects and, even if assessment measures that overcome floor effects have been employed, sensory impairments or other physical changes that are progressive with age may reduce test performance attributing to performance decline. Despite these methodological difficulties, advances have been made in understanding the aetiology, the neuropathological and clinical manifestation of DAT in PWID with and without Down’s syndrome.

1.3 Assessment of dementia

The diagnosis of dementia in the general population is arrived at via an array of different types of retrospective assessments whereby declines in cognitive and adaptive functioning reported by family members or the patient themselves, are measured objectively from the time of initial examination. (Silverman et al., 2004). An example of a retrospective assessment tool is the CAMDEX (Roth et al., 1986). This tool collates information systematically incorporating a history from the relative, physical examination and a neuropsychological assessment called the Cambridge Cognitive Examination (CAMCOG). This type of tool provides means of quantifying the severity of impairment along several scales as well as cut off points for the diagnosis of dementia. These tools have been developed over many years and now provide evidence of differentiation in dementias as well as other conditions such as depression (Heilman & Valenstein, 2003).
As yet there are no standardized assessment tools for clinicians to use with people with Down’s syndrome to accurately diagnose conditions such as dementia (Strydom & Hassiotis, 2003). Many rating scales have been developed to assist in diagnosis and assessment and many pre-existing tools intended for other purposes have been modified for use with PWID, for example the modified CAMDEX informant interview (Sano et al., 2005). The International Association for the Scientific Study of Intellectual Disabilities (IASSID) have, over the past ten years, published guidance advocating a prospective tripartite approach to assessment (Burt & Aylward, 1999). A baseline of premorbid functioning is recommended in early adulthood when the individual is presumed healthy followed by reassessment every five years unless dementia is suspected and a yearly assessment is required. This requisite for baseline assessment arises as currently there is an absence of normative data for normal ageing in people with Down’s syndrome. Unlike in the general population, a PWID cannot be compared to his fellow cohort to see whether deterioration is a result of normal ageing or the onset of a condition such as dementia. A longitudinally assessment allows the clinician to compare an individual’s pre-morbid functioning to their current functioning.

When deterioration is indicated a careful and accurate diagnosis of dementia is required. This diagnosis can be viewed as an exclusive process whereby all other possible explanations for the deterioration are explored, for example, dementia-like symptoms can manifest in conditions such as depression, sensory impairments and hypothyroidism, both prevalent in people with Down’s syndrome (Burt & Aylward, 1999). Thirdly, following diagnosis the client and those that care for him/her need to receive a service that is titrated to their nature and level of need.
IASSID recommend, as well as cognitive functioning being assessed prospectively, adaptive functioning, emotional control, motivation and social behaviour be assessed too given the emerging evidence on changing personality and behavioural features in the early onset of DAT. If deterioration is found, IASSID recommend using the ICD-10 diagnostic criteria for dementia as it places more emphasis on these non-cognitive aspects e.g. emotional lability, irritability and apathy. In addition ICD-10 adopts a dual diagnostic approach in which a diagnosis of dementia is established first and then DAT is differentiated from other forms of dementia. IASSID propose the use of a battery of tests for diagnosis of dementia, this battery includes informant interviews, rating scales and neuropsychological assessments that assess the cognitive, adaptive and emotional domains requisite for a diagnosis of dementia. They assert this battery is useful for most PWID although ongoing problems for assessing people with severe and profound difficulties remain due to floor effects.

These extensive batteries can be time consuming and laborious therefore single time point assessment tools would be more clinically useful. Certainly, in the older adult field, informant interviews and direct assessments of mental status such as the MMSE (Folstein, Folstein & McHugh, 1975) provide informative results from a single administration in most cases. These, of course, are used in conjunction with psychiatric, medical and neuropsychological information. Silverman et al., (2004) have argued that if practical methods for making a valid and timely diagnosis of dementia were available for PWID this would reduce the need for extensive testing. They conducted a study using an informant interview, the Dementia Questionnaire for Persons with Mental Retardation (DMR) (Evenhuis, 1995) and a direct assessment of mental status, the
Institute for Basic Research Evaluation of Mental Status (IBR) (Wisniewski & Hill, 1985), along with additional direct assessments of cognitive functioning on a sample of 273 adults with ID, including 186 with Down’s syndrome. They found both DMR and the IBR showed promise in classifying the dementia status of PWID investigated i.e whether dementia was present or not. There are limitations to these findings though, as Silverman et al., (2004) acknowledge. The IBR was not designed to be sensitive to the earliest stages of DAT and should not be used solely in diagnosing dementia. Equally as best dementia practice advocates, informant measures should be used in conjunction with direct assessment tools.

This work on identifying screening tools is timely as cholinesterase inhibitor medication are starting to be used with people with Down’s Syndrome and DAT (Lott, Osan, Doran & Neslon, 2002; Prasher, Huxley & Haque, 2002; Prasher 2004; Prasher, Fung, Adams, 2005). National Institute of Clinical Excellence (NICE) guidelines for cholinesterase inhibitors requires ongoing monitoring of cognitive decline with a recommendation of terminating treatment when a significant decline occurs, in the general population this is 12 points or less on the MMSE (NICE, 2001).

It is apparent that research for single time point assessments is embryonic and that currently comprehensive batteries still provide the best information requisite for a diagnosis of dementia in PWID. Nonetheless, the pragmatics of conducting this type of testing in a clinic are limited due to the length of testing required plus the increased demands on a clinicians time and resources.
1.4 Section summary

Although the risk of DAT in people with Down’s syndrome has been known for sometime, theories for the apparent gap between the presence of neuropathology of DAT and the clinical manifestations have only just begun to emerge. Research has shown biological factors such as atypical karotypes, genetic susceptibility as well as oestrogen and gender differences can impact on the development of DAT, although these studies are subject to methodological concerns that weaken their conclusions (Schupf, 2002).

The cognitive reserve model offers stronger evidence in explaining the gap, particularly in people with Down’s syndrome due to the presence of abnormal frontal lobe development. Holland et al., (2000) hypothesise that pre-morbidly impaired frontal lobes are susceptible to the neuropathology of plaque and neurofibrillary formation, leading to frontal dementia like symptoms, namely changes in personality and behaviour, prior to the clinical manifestation of DAT. Whilst reviewing these studies it was apparent that methodological problems hamper finding consensus on issues such as diagnostic criteria for DAT, prevalence and incidence of DAT in PWID with and without Down’s syndrome. There was also a reported paucity of standardised assessment tools.

Despite these difficulties, studies have advanced knowledge on the neuropathological and clinical manifestations of DAT in PWID with and without Down’s syndrome. Assessment and diagnostic guidelines have been published by organisations such as IASSID, particularly advocating the use of prospective assessments. Work has also begun on identifying single time point assessment tools for dementia screening.
The next section will examine the current picture of service provision for ageing PWID and discuss the options available to clients and carers following a diagnosis of dementia, namely accommodation and day services options.
2. Service Provision

2.1 The current picture

Hatzidimitriadou & Milne (2005) argue that in the UK the current picture of service provision for ageing PWID is characterized by fragmentation and limited choice of resources and specialist care. They report that service planning is often incoherent, that many older people with ID and their carers' receive poor quality non-specialist care and that staff are inadequately trained to manage the often multiple and complex needs of this client group. Cooper (2003) argues that in contrast to the older adult population, there are a lack of services with professionals skilled in the diagnosis and management of PWID and dementia, as well as a lack of training and awareness of direct care staff and primary care professionals of the changes which might indicate the onset of dementia.

McCarron & Lawlor (2003) reviewed policy and services in Ireland and raised the question of who was best placed to provide a service to an ageing ID cohort, either generic older adult services or ID services. They argue that on one hand generic psychogeriatric services and memory clinics offer a model of service development and post diagnosis care provision. However, these services may not have the sufficient skill mix amongst professionals to meet the needs that manifest from having a intellectual disability. In addition, it is assumed by McCarron & Lawlor (2003) that these mainstream services are always willing to assess and treat PWID, yet accessing these services continues to be problematic for PWID (Cooper, 2006). PWID’s age is often an obstacle to accessing geriatric services, who see people 65 years and older. PWID may be too young to be referred to geriatric services despite having similar needs to older
service users in the general population. With regard to ID services, PWID continue to have special needs over and above those determined by their dementia and therefore the experience and specialist knowledge situated within ID services may be better placed to provide services for this client group. There may be, however, a shortfall in knowledge and skills as ageing ID research and practice is still in its infancy (McCarron & Lawlor, 2003).

This debate on which services provide dementia assessments and care management is not unique to ageing PWID. Beattie, Daker-White, Gilliard and Means (2002) reviewed the literature on younger people with dementia (under 65 years of age) from the general population and identified existing recommendations for specialist, flexible, age appropriate and dedicated services. Yet they found a disparity between what was being recommended and what was being provided, reporting that people’s needs remained unmet as they were too young for geriatric services but were also not within the remit of generic mental health services due to having dementia.

2.2 Service models for dementia assessments

In the general population the memory clinic model of service provision is utilised and offers early specialist assessment and brings together expertise from different professionals. This model has been successful in providing a service to dementia patients and their families (Van Hout, Vernooij- Dassen & Hoefnagels, 2001). Attempts have been made to introduce this model to the intellectual disability field namely in Canada (McCreary, Fotheringham, Holden, Ouellette-Kuntz & Robertson, 1993) the USA (Chicoine, McGuire & Rubin, 1999) and recently in the UK (Hassiotis, Strydom, Allen
& Walker, 2003). Hassiotis et al., (2003) set up a memory clinic as a joint venture between psychiatry for the elderly and ID services and developed an assessment protocol, based on the same principles as the mainstream memory clinic but with modifications in the choice of instruments that were applicable to the population with ID. In addition, there was a wider remit than traditional clinics as they included a proactive screening programme as recommended by IASSID (Aylward et al., 1997). The authors concluded that the framework of a memory clinic was useful in the evaluation of ageing clients with intellectual disabilities including Down’s syndrome. They also found this model had potential to be an important resource for research and training of other health professionals and carers. However, they had set up this clinic within existing resources and argued that for long term provision extra resources would be needed, to cope with the additional administration and clinical issues.

Possible drawbacks of this memory clinic model for PWID are the assumption that bringing a PWID to a clinic will provide an accurate picture of their current skills and functioning. It could be argued that assessing someone in their home, as oppose to an unfamiliar clinical environment, may give a more accurate picture, given that they are in familiar and less stressful surroundings to demonstrate their cognitive and adaptive abilities.

Also memory clinics require expertise from professionals that may not be easily available therefore people may have to travel some distance in order to receive an assessment. One solution that has been proposed by McCarron and Lawlor (2003) is to offer multi-disciplinary specialist teams delivered through mobile regional ID dementia
clinics. They argue these mobile clinics would address the shortage of expertise and the obstacles to accessing services particularly in rural areas. They recommended a mobile model for service provision with the following components (1) diagnosis and assessment (2) multi-disciplinary assessment and clinical support (3) comprehensive person centred services (4) advice on environmental modification and finally (5) staff and family education and training. McCarron and Lawlor do not give details as to how this model could be operationalised and it is speculated that additional financial and administration resources would be required to fund such a service model.

2.3 Models of dementia care

Following the assessment of and diagnosis of dementia in PWID, increased health and social care needs can be expected and services need to plan accordingly. Jokinen (2005) found a paucity of literature regarding service provision guidance with the majority of articles taking a biomedical stance and assessment and diagnosis forming the second largest group. Service and care management articles were the least frequent. Reassuringly though, the number of service and care management articles had tripled when comparing the periods 1995-1999 and 2000. These guidance articles, regarding service provision and staff guidelines, gave practical suggestions for agencies facing challenges in providing day to day care (Hammond & Benedetti, 1999) as well as guidance on ways PWID with dementia’s communication can be helped in coping with diminished capacities, memories and verbal skills (McCallion, 1999).

Janicki, McCallion and Dalton (2003) have developed models of community care and published guidance for providers and care agencies when meeting a clients changing
dementia needs. The ‘ageing in place’ model proposes that a person remains in their accommodation with appropriate supports adapted and provided. The second model known as ‘in place progression’ promotes that the staff and the environment are continually adapted to become increasingly specialized to provide long term care for the person with dementia within the residential service (but not necessarily their own accommodation). The final option is ‘referral out’ where the person is moved out to a long term nursing facility or other type of provision (Janicki et al., 2003).

Wilkinson, Kerr, Cunningham & Rae (2004) examined these models of care experienced by PWID and dementia, as part of their study into exploring current models of practice for supporting people with ID and dementia. They found, from the 6 sites they visited, that ‘ageing in place’ was the option many staff were endeavoring to pursue however, only one site had nursed a person through to their death. At this site staff reported using a number of measures to ensure and maintain the level of care required. For example, utilizing a team of trained volunteers to supplement paid staff and these volunteers supported the residents without dementia. These extra staff enabled the paid staff to dedicate their time and resources to the person with dementia. The manager of this site acknowledged that they were caring for one person with dementia and if this number were to increase, the feasibility of maintaining this model could be problematic due to the high level of resources required.

Wilkinson et al., (2004) found no examples of ‘in place progression’ whereas most sites had experience of the ‘referral out’ option, with referrals made to hospitals and care/nursing homes for older people. Wilkinson et al., (2004) found that with one
exception, this option was seen as a negative experience, being detrimental to both a person's health and well being. Indeed, Thompson and Wright (2001) reported worrying experiences from carers and staff, in their large scale survey of residential services for older people, of PWID and dementia rapidly declining, or in some cases dying, following a move to a care home. They concluded that a lack of staff awareness and training plus limited contact with ID services made care/nursing homes inappropriate options of care for PWID and dementia. Wilkinson et al., (2004) concluded from their study that the complexity of the needs and demands associated with supporting PWID and dementia meant that, currently, all three options and a combination of aspects of each model would be used.

2.4 Service planning

For these models of assessment and care to be implemented, commissioners and service providers need to be informed of this ageing cohorts needs. Watchman (2003) argues that there is a lack of consistent and accurate information available for service planners and providers of care for people with intellectual disabilities, in particular those with Down’s syndrome and dementia. This leads to difficulties in achieving the co-ordinated approach that is required to ensure a needs led multidisciplinary approach to planning and commissioning services. Watchman (2003) also argues that clear protocols and procedures are essential in order to establish a multidisciplinary service response for people with intellectual disabilities and dementia. This should include guidelines for partnership and strategic planning between statutory, voluntary and private agencies. These issues have also been posited by Dodd, Turk & Christmas (2001) in their briefing for commissioners. In addition, they argue that commissioners require greater
knowledge and understanding of this population and their needs to ensure they have the
resources required to plan and deliver effective and high quality services. One
suggestion is to create a service development strategy underpinned by national and
international epidemiological data on the older population with ID.

Commissioners and providers also need to be aware of the range of issues facing this
ageing cohort, for example the need for appropriate accommodation, carer stress and the
increased health needs of ageing PWID. Age related problems impact on PWID at an
earlier chronological age than the general population and are at greater risk of
developing arthritis and rheumatic illness, cardiac and pulmonary conditions plus
sensory impairments (Grant, 2001). With regards to mental health, this ageing ID cohort
are at risk of developing psychiatric disorders with a prevalence rate of 20% for major
psychiatric disorders such as depression and anxiety in PWID over 65 years (Bland,
Hutchinson, Oakes & Yates, 2003). High levels of unmet physical and psychiatric needs
exist and ensuring access to health services remains a significant challenge for service
development, particularly addressing structural and cultural barriers to accessing
services, and increasing awareness and training amongst health professionals.

2.5 National and local ID policy

Along with challenges in commissioning services, national and local policy remains
unclear and, crucially, without dedicated funding. Unlike the National Service
Framework (NSF) for older people which outlines how dementia services are developed
and operationalised, professionals working with ageing PWID encounter fragmented and
poorly organized services.
The white paper Valuing People (Department of Health, 2001a) is based on the principles of rights, independence, choice and inclusion and emphasizes the importance of effective partnership between people with ID, their families, statutory agencies and the independent sector. It highlights the needs of older people with ID, in particular, the need for services to adopt person-centred planning approach when considering how to meet the person’s needs as they change due to physical and mental decline. It also emphasises that this group is not homogenous and therefore a ‘one size fits all’ approach will fail both clients and their carers. Yet it does not specify what approaches should be available to accommodate the heterogeneous needs of this ageing cohort, failing to outline options for accommodation and day services. It also sets out a vision of generic older adult services, mental health services and ID specialist services working together in partnership but it does not specify how this is to be achieved at the local level.

Not surprisingly this lack of clarity at the national level has resulted in underdevelopment in services at the local level. Learning Disability Partnership Boards (LDPB) are tasked with implementing these aforementioned policy aims and represent the strategic vehicle for inter-agency planning and commissioning for people with ID living in the locality (Department of Health, 2001a). The boards bring together public, private, community and voluntary sector organizations as well as service users and carers. LDPB’s have a special responsibility to ensure co-ordination between ID and generic older people’s services yet a survey by the Foundation for People with Learning Disabilities in 2003 found this was not occurring with serious concerns over lack of resources and capacity. Further evidence from the Department of Health (2004) and the
Learning Disability Task Force (2004) suggests that few local authorities have fully
developed plans for meeting the needs of older users with ID.

This lack of clarity, both at local and national policy level, can be assumed to result in
patchy service provision. Fitzgerald (1998) conducted a study of service provision for
older people with ID and found considerable variation in the provision of services and
widespread confusion about which agencies and professionals were responsible for
providing services for this client group. Problems identified in other studies include lack
of investment in specialist services for this client group, low expectations of users by
staff, limited commitment to maintaining user independence, low levels of stimulation or
rehabilitation and few opportunities for users to develop networks with others of a
similar age or who share similar interests (Aspray, Francis, Tryer & Quilliam, 1999;
Dagnan & Ruddick, 1997; Duff, Houghton & Scheepers, 2000; Hassiotis, Barron &
O’Hora, 2000).

Hatzidimitriadou & Milne (2005) conclude their review with recommendations for
effective service development namely an established strategic framework for planning
(such as LDPBs) to which all key relevant stakeholders are committed and contribute; a
partnership between ID agencies and older people’s services with support from mental
health trusts and housing agencies; a service plan for older people with ID and their
carers underpinned by dedicated funds; evidence of the extent and nature of existing
service provision; flexibility of commissioning; and recognition of workforce and
training issues. However, others have acknowledged there are challenges to this vision
namely the problems of co-ordinating diverse care systems and developing partnerships between a variety of providers and agencies (Wilkinson & Janicki, 2002).

2.6 Section Summary

The current picture of service provision is characterized by fragmentation and limited choice of resources and specialist care. Despite studies advocating guidelines and models of practice for supporting PWID and dementia, national and local policy remains unclear. Guidance on how to operationalise the key principles identified in Valuing People, such as cohesive working between generic older adult services, mental health services and ID services, have not been forthcoming, leaving LDPB struggling to implement these policy aims resulting in serious concerns over the lack of resources and capacity for this ageing cohort. Despite recommendations being advocated by researchers and organisations such as, Foundation for Learning Disabilities, to improve this fragmented picture, challenges remain of co-ordinating these diverse care systems and improving dialogue within and between services involved in providing health and social care to this client group.

With these challenges in mind, the next section will explore the service provision for older adults with dementia, namely the memory clinic model and person-centred approaches to care. The issues that arise when attempting to meet the dementia assessment and intervention needs of the general population will be examined.
3. Service provision for older adults

3.1 The assessment model

Service provision for people with suspected and diagnosed dementia in the general population is primarily delivered through primary care and specialists services such as memory clinics. The earliest memory clinics began in the 1980’s and were mainly academic centres with different specialities running them according to their expert interest for example psychiatry, neurology or geriatric medicine (Dening, 2003). Currently many memory clinics reside in old age psychiatry services and are part of the service model for dementia set out in the National Service Framework for Older People (NSF) (Department of Health, 2001b).

The ethos of the memory clinics is to provide early diagnosis as well as advice on how to manage the condition (Foreman, Gardner & Davis, 2004). The benefits of early diagnosis are recognised by the NSF for Older Adults, ‘if dementia is not diagnosed early, carers can become demoralised due to lack of recognition and support and having to cope with apparently unexplained behavioural changes’ (Department of Health, p. 97, 2001b). Passmore and Craig (2004) in their discussion on the future of memory clinics identified the following benefits of early diagnosis: access to treatments, planning of future care, helping the family to come to terms with prognosis and help to understand changes in memory, behaviour and personality. Memory clinics are typically multi-disciplinary and usually a patient will see psychology, psychiatry, sometimes nursing and social work disciplines in a one session appointment (Simpson, Beavis, Dyer & Ball, 2004).
Lindesay, Marudkar, Diepen and Wilcock (2002) found from their survey of 58 operational memory clinics that more than half the clinics (55%) reported that they had been set up specifically to assess for DAT. This remit was attributed to the licensing of cholinesterase inhibitor drugs such as Donepezil and the development of services for early onset dementia. Lindesay et al., (2002) found that the service model had evolved over the years moving from an academic ethos to one that incorporates elements of old age psychiatry services. They found that the assessment tools and protocols included the MMSE, physical examination, thyroid function, full blood count, hepatic and renal function, B12 folate and blood glucose. Most clinics used CAT and MRI scanning, as well as standardized assessment of cognitive functioning with Mini Mental State Examination (MMSE) and CAMCOG being the most commonly used instruments. There is no definition of what constitutes an ideal memory clinic and they may be structured to provide either assessment or treatment, although many provide both (Passmore & Craig, 2004).

3.2 Old age psychiatry services

As memory clinics have become more established a debate has evolved on whether this service model is superior to largely multi-disciplinary old age psychiatry services that handled a range of mental health problems, not just dementia. Luce, McKeith, Swann, Daniel and O'Brien (2001) investigated how memory clinics (MC) compared with traditional old age psychiatry (OAPsy) services by examining referrals to a memory clinics (n=100) and old age psychiatry services (n=100). The authors compared the referrals on demographic variables, cognitive function and diagnoses. Luce et al., (2001) found that the MC patients were significantly younger, had lower levels of cognitive
impairment and a wider range of diagnosis. The MC patients diagnosed with dementia were also found on average to be two years earlier in the course of the disease compared to OAPsy patients with dementia, thus receiving treatment earlier.

A recent paper by Simpson, Beavis, Dyer and Ball (2004), however, has disputed the benefits of memory clinics and found that domiciliary visits (DV) and attendance at memory clinic shared more similarities than differences in terms of care management. Their study compared referrals for MC and DV utilising a retrospective case note review, collating the clinical features and a 18 month prospective follow up examining the subsequent clinical management. The researchers concluded the only difference between the groups was administration of psychotropic medication being less in the memory clinic group. They argue that a rapid response in the patient's home affords accurate diagnosis and serves to introduce an immediate management plan tailored to the patient and carer. A major drawback with this study is that it was naturalistic and patients were assigned to memory clinic or DV by the wishes of the referrer therefore the increase in psychotropic medication could be due to the patients needing home visits due to their behavioural and psychological complications rather than problems with their memory.

Whether a memory clinic model or old age psychiatry services are utilised, Luce et al., (2001) highlight the double edge to early diagnosis of dementia, on the one hand it offers improved access to anti-dementia medication and delayed admission to long stay hospitals and nursing care, on the other hand there are increased financial resources needed to provide this service which may be prohibitive. Nonetheless they concluded
that whatever the financial costs, the potential benefits of early diagnosis for quality of life of patients and carers should not be underestimated both in terms of access to treatment services, support networks and in terms of obtaining information and preparing for the future.

3.3 Experiences of memory clinics

Studies canvassing the views of clients and carers in relation to their memory clinic experiences have found satisfaction as well as concerns. Foreman, Gardner and Davis (2004) found amongst 238 participants (93 caregivers and 45 clients) an overall satisfaction however only 55% of caregivers were satisfied with the advice received regarding how they should deal with, or manage their relative’s condition. Van Hout, Vernooij-Dassen, Hoefnagels and Grol study (2001) also found carer and client dissatisfaction with the vagueness of diagnostic information communicated to patients and relatives and the insufficient nature of the information and advice offered to relatives. This study also included GPs, the primary referrer to a memory clinic, and although they rated overall satisfaction they were also dissatisfied with the limited advice given, particularly on how to further manage patients and caregivers in the post diagnosis period. Although memory clinics are widely used and embedded in government policy for delivery of dementia care services, Passmore and Craig (2004) have argued that there is a need to evaluate clinics structure and management to prove definitively the benefits for patients and the NHS.
3.4 Dementia care

Although attempts have been made to bring a psychosocial dimension to the assessment and diagnosis of dementia (Pratt & Wilkinson, 2003, Moniz-Cook & Woods, 1997, Moniz-Cook, Agar, Gibson, Win & Wang, 1998) it remains dominated by a neuropathological paradigm (Kitwood, 1997). In terms of dementia care following diagnosis, an attempt has been made to adopt a different paradigm, to move from a reductionistic neuropathological explanation to a psychosocial person centred approach.

Tom Kitwood (1997), a key proponent of person centred approaches, was keen to challenge the deterministic and reductionistic views of dementia promulgated by psychiatry and allied disciplines and instead develop ideas to enhance well being through quality care practices. Kitwood (1997) challenged the standard paradigm that mental and emotional symptoms of dementia are solely a result of a catastrophic series of changes in the brain. He argued that these neurological changes alone are insufficient to explain how the disease occurs in specific cases and that the biography of the dementia patient and their social and emotional history and the ways in which interactions with the individual may in itself enhance ill being or conversely (in case of good quality care), well being.

Kitwood (1997) perceived an entrenched malignant social psychology existing in dementia care whereby the person’s behaviour is viewed as meaningless by staff and a result of neuropathological decline. He argued that the unique subjectivity of the person, their unique way of experiencing life and relationships will bring a unique way of experiencing dementia and should be acknowledged. Placing the psychosocial factors
central to an explanation of dementia allows for the PERSON-with-dementia rather than person-with-DEMENTIA to be viewed. Kitwood argued that if a person-centred approaches are used in dementia care the person can live with the often confusing and troubling symptomology without the need for medication, crisis intervention and hospitalisation and even recover skills and abilities through a process known as rementing. (Karlsson, Brane, Melin, Nyth & Rybo, 1988; Murphy, Lindesay & Dean, 1994). In terms of evaluating these person-centred approaches Dementia Care Mapping (DCM) has been developed both as an instrument for developing person centred care practice and as a tool in quality of life research (Brooker, 2005). DCM provides a vehicle for those wishing to systematically move dementia care from a task focused and holding environment to one that respects people with dementia as human beings (Fossey, Lee & Ballard, 2002).

3.5 Section summary

It is evident in this chapter that memory clinics have an important role in the early detection and diagnosis of dementia. Reported benefits include access to treatments, planning of future care, helping the family to come to terms with prognosis and help to understand changes in memory, behaviour and personality. Debate exists over the future of memory clinics, particularly against the widespread growth of multidisciplinary psychogeriatric services and calls for systematic evaluation have been raised.

In terms of service satisfaction patients, caregivers and GP’s had positive opinions about the diagnostic value of the clinics although advice how to manage the condition given to both carers and GP’s could be improved.
Dementia care practices have been challenged by the work of Tom Kitwood and colleagues, who call for a humane and compassionate approach to managing dementia. DCM has been developed to assist care provisions in moving from a reductionistic and deterministic view of a person’s dementia experience to one that acknowledges their unique subjectivity and personhood. Studies have reported significant reduction in distressing symptoms and, in some cases a recovery of skills through the process of re-menting, once the environment and the personhood have been acknowledged.

In the next section an issue from clinical practice will be explored, namely the disclosure of a diagnosis of dementia to patients and their carers. The dilemmas and issues arising for clinicians, the carers and the patients themselves will be discussed.
4. Disclosure of dementia diagnosis

4.1 A need for disclosure

The issue of disclosing a dementia diagnosis has been extensively debated in the literature ranging from the views of GPs, mental health professionals, relatives and carers to the patients themselves. With a political and strategic impetus to create a patient led service comes a drive for greater information to patients about their conditions (Department of Health, 2001b). NSF for Older People has specifically identified the importance of early diagnosis of dementia in enabling people and their families to respond effectively (Department of Health, 2001b). The NSF clearly indicates that treatment of dementia ‘always involves explaining the diagnosis to the older person and any carers and where possible giving relevant information about sources of help and support’ (National Service Framework, p.98, 2001).

Evidence from studies investigating whether people would like to know their diagnosis suggests that people with dementia want to know. Jha, Tabet and Orell (2001) reported in a study investigating older adults’ reactions to receiving a diagnosis of dementia compared to depression, more than 75% (n=53) of their participants preferred to know their dementia diagnosis, even if caused upset and this included people with severe dementia (as measured by MMSE score of less than 15). A recent study from Australia replicated an early study by Erde, Evan, Nadal and Scholl (1988) and looked at attitudes of young people towards disclosure before and after a session of psycho-education about dementia. They found that 93% of participants indicated a desire to be informed of a
diagnosis of dementia of the Alzheimer’s type (DAT) following the psycho-education session (Sullivan & Connor, 2001). It could be argued that these participants were able to make this decision as they were currently not at risk and likely to be many years from possibly developing the disease. Another study addressed this issue by asking older adults without dementia what they would like to know and in a sample with a mean age of 78 years the figure was still high, with 80% of participants reporting they would like to be told of their dementia diagnosis (Holroyd, Snustad & Chalifouk, 1996).

Early diagnosis allows individual patients and their carers a number of decision making opportunities, in particular about practical, legal and financial provisions for the future and may help the introduction to appropriate services and support networks (Wilkinson & Milne, 2003). As well as practical benefits there are moral issues to consider as Pinner (2000) argues ‘the moral doctrine of diagnosis disclosure is derived from a respect for the patient’s autonomy as well as beneficence’ (p.514). She also highlights the difficulty for clinicians in deciding what information to give, how one reconciles the patient’s autonomy, namely the ability to self govern and make one’s own decisions, with non-maleficence, that is the obligation not to inflict harm intentionally. While diagnostic disclosure is fundamental to enhancing patient autonomy, it has been argued that patients also have the right not to know (Buckman, 1996). This presents a dilemma for the clinician responsible for disclosing information to a patient, as they need to gauge accurately what the patient may want to hear.

In attempting to understand this dilemma, research in past years has concentrated on the disclosure of a cancer diagnosis. The ‘breaking bad news’ literature, primarily stemming
from the cancer disclosure studies, has highlighted the difficulties in ascertaining what
patients want to hear. However well bad news is broken it can leave patients with major
concerns about their predicament, whether these are physical, social, psychological or
spiritual in nature. Yet direct observations of bad news consultations have found most
cancer specialists make assumptions about what the patient already knows, consequently
some are given too much information and others too little. (Maguire, 1998). Several
versions of guidelines have been published to assist physicians in communicating bad
news to their patients (Ptacek & Eberhardt, 1996; Fallowfield & Jenkins, 2004). These
guidelines appear to assume that medical interactions in which bad news is delivered are
linear in format and essentially composed of three chronologic stages: preparing to
disclose the news, disclosing the news, and responding to reactions to the news. Eggly et
al., (2006) have challenged this linear model and suggest that these interactions are
complex and dialectical and that guidelines should be revised to accommodate the social
context in which news is broken.

It appears that the cancer field is more advanced than the dementia field as guidelines
and models to understand disclosing practice are embryonic. Vassilas and Donaldson
(1998) also found that health professionals are more likely to disclose information to
people with cancer than people with dementia. One reason posited for this decision is
that there are notable differences between dementia and cancer namely, in dementia, the
illness is intrinsically altering the patient’s cognition, their insight and their ability to
make judgements thus affecting the patient’s sense of self (Pinner, 2000).
In the absence of a diagnosis it remains hard to offer support to minimise the burdensome impact of the disease process. Clare (2003) argues that patients will be aware that something is wrong but remain isolated in their uncertainty and this can have a knock on effect to those caring for the patient with family caregivers experiencing episodes of depression, immune system disorders, increased consumption of psychotropic drugs and increased mortality (Schulz & Beach, 1999). Research has demonstrated that a timely diagnosis and disclosure may prevent crises, facilitate adjustment and provide access to a range of treatments and support (Woods, Moniz-Cook & Iliffe, 2003). Also with the development of new drug regimes that can slow down the progression of the early stages of dementia, the disclosure of diagnosis has gained prominence as clinicians require consent before commencing treatment. The responsibility of the early detection of dementia and subsequent intervention often falls to GPs as a patient or carer will present to primary care with concerns however the detection and subsequent diagnosis of dementia appears to be fraught with difficulties.

4.2 GPs disclosure practice

GPs have a pivotal role in the early identification and subsequent management of dementia and often act as gatekeepers to more specialised services such as memory clinics. The first step towards a disclosure is accurate diagnosis yet research has found accurate detection of dementia by GP’s to be varied with reports of 25% in Sweden (Olafsdottir, Skoog and Marcusson, 2000) and 50% in Australia (Bowers, Jorm, Henderson and Harris, 1990). However Iliffe (1997) reported that GPs often have a much higher rate of diagnostic accuracy than evidenced by research. Milne, Woolford, Mason and Hatzidimitriadou (2000) argue that attitudes towards detecting early stages of
Dementia may underpin the variability of detection rates. Van Gool and Van Crevel (1996) commented that historically GPs have been reluctant to diagnose dementia because they feel unable to offer effective treatment. In the Olafsdottir et al. (2000) study, the researchers suggest that low detection arises from time constraints and a possible belief, held by GPs, that diagnosing dementia carries no benefits to the patient.

Milne et al. (2000) aimed to explore the 'myths', namely no benefits, risk of misdiagnosis, and the potential to emotionally damage the patient and/or their carer, that might underpin GPs' reluctance to diagnose and therefore disclose. Questionnaires were sent to 310 GPs, requesting agreement or disagreement with five statements and 182 were returned (58.7%). They found that GPs' motivation to practice early diagnosis is fuelled by positive and negative considerations, for example, that both intervening early is beneficial to patients and that failing to intervene may be harmful. Supplementary qualitative data revealed that attitudes towards early diagnosis were underpinned by specific beliefs. Milne et al. (2000) found that those GPs committed to early diagnosis view it as facilitating preventive intervention and as enabling them to offer treatment and services at a stage when they can be most effective. Of particular note was being able to offer preventive support to carers which may delay admission to residential care of their family member.

Disclosure was identified as a key component of the overall process of diagnosis. GPs committed to early diagnosis defined their role broadly to include discussing the implications of the diagnosis for patients and their family, exploring options for the future and advising about services. Those GPs who did not support early diagnosis
commented on resource deficits such as time constraints and that diagnosing dementia early increases demand on already overstretched resources. It may also raise expectations where there are limited treatment options and finally it may be emotionally damaging and increase the onset of depression.

Although studies report variability in GPs diagnostic accuracy (Bowers, Jorm, Henderson & Harris, 1990; Iliffe, 1997; Olafsdottir, Skoog & Marcusson, 2000) it is apparent that difficulties in establishing a diagnosis impact on a clinicians ability and confidence to disclose. Cody, Beck, Shue and Pope (2002) conducted a study of diagnosis and disclosure practices of primary care physicians (PCP) in Arkansas, USA. They found from a sample of 142 that 54% had difficulty establishing a definitive diagnosis and that 30% responded that they had difficulty telling the patient the diagnosis. Those who reported difficulty establishing a diagnosis were more likely to have difficulty disclosing it. Interestingly the participants were more likely to tell the patient if they were sure the patient had dementia (88%) than if they suspected it (73%). Cody et al., (2002) concluded from their study that a difficulty in making a diagnosis was correlated to a difficulty in disclosing, therefore they argued that improving education about assessment for dementia would increase confidence in diagnosis thus making it easier to disclose. Pinner (2000) argues that there are clear and accurate diagnostic criteria for Alzheimer’s disease, for example in ICD 10 or DSM IV allowing clinicians to feel increasingly confident in their diagnosis.
4.3 Psychiatrists and mental health professionals' disclosure practice

Rae, McIntosh and Colles (2001) reported that disclosing a diagnosis was rated as the fifth most difficult aspect of dementia management by GPs but these difficulties have also been found amongst clinicians in memory clinics and old age psychiatry services (Gilliard & Gwilliam, 1996; Johnson, Bouman & Pinner, 2000). A recent qualitative study by Keightley & Mitchell (2004) with mental health professionals, concluded that the main influence on professionals’ disclosure practice was lack of certainty about whether the person with dementia would want to know their diagnosis or not, which was, in turn influenced by professional’s perceptions of dementia and their sense of the impact of knowing. The participants reported a sense of hopelessness and helplessness that the authors linked to the professionals perception of dementia as something ‘worse than death’ with an inevitable course. With regard to psychiatrists who are primarily responsible for disclosure in memory clinics and old age psychiatric services, Clafferty, Brown and McCabe (1998) found that only 44% of their sample informed their patients of their diagnosis of dementia. One criticism of this study is that Clafferty et al., (1998) sent a questionnaire to all consultant psychiatrists in Scotland asking them to comment on their disclosure practices for a range of psychiatric disorders. Therefore many of the participants would not have encountered the scenario of disclosing a dementia diagnosis.

The discussion so far has focused on professionals reasons to disclose yet few studies have explored how disclosing a dementia diagnosis impacts on the clinician psychologically. This is surprising given the extensive cancer literature on physicians’ experiences of breaking bad news, particularly how it can be stressful, even after completing a disclosure encounter with the patient severally hours earlier, and how
appears to effect junior and inexperienced physicians more (Ptacek, Ptacek & Ellison, 2001). It could be hypothesised that the dementia field is embryonic in considering these issues and in time researchers will move from the risks and benefits of a disclosure to the psychological impact on delivering and receiving a dementia diagnosis.

4.4 Risks and benefits of disclosing a dementia diagnosis

The possible risks and benefits of a disclosure perceived by clinicians have been highlighted in the aforementioned studies with GPs and mental health professionals, focusing on the advantages and disadvantages of disclosing. One reported disadvantage is the possible risk of causing emotional distress that may manifest from receiving the diagnosis and may bring an onset or exacerbation of depression, induce feelings of hopelessness, and a catastrophic reaction (Ahujun & Williams, 2000; Clafferty, 1999; Keightley & Mitchell, 2004) or even suicide (Rohde, Peskind & Raskind, 1995). Studies of patients' reactions following disclosure found a range of emotions were experienced including shock, anger and fear as well as negative effects on self confidence and esteem (Husband, 1999; Pearce, Clare & Pistrang, 2002). In contrast Pratt and Wilkinson (2001) argue that a disclosure can in fact be a relief and validation rather than a distressing experiencing as the individual has an explanation for the changes that they had recognised in themselves.

Clinicians have also described patient's poor insight into their condition as a reason for not disclosing (Rao, 1997) with Pinner (2000) stating that in the late stages of the disease the truth will neither benefit nor harm and disclosure is merely futile. Rice (1997) surveyed old age psychiatry consultants and found 38% 'nearly always' informed mildly
demented patients but in the case of moderate and severe dementia only 13% and 6% respectively discussed the diagnosis with patients. There were similar findings in a survey of geriatricians but geriatricians appeared to inform patients with mild dementia of their diagnosis more frequently than their carers (Rice, Warner, Tye and Bayer, 1997). What is interesting about these findings is the possible inconsistency between clinicians arguing that a disclosure may have a profound negative impact on the patients' mental health yet also arguing that a patient may have poor insight and would be unable to retain and comprehend the explanation. One may wonder if a patient cannot comprehend and remember a disclosure how they are supposed to become depressed.

Another major finding regarding clinicians' reasons for not disclosing dementia concerns the idea that there is little that can be offered in terms of effective treatment (Clafferty, 1999; Downs, Cribbens, Rae, Cook & Woods, 2002; Milne et al., 2000). Unlike cancer where significant advances have been made to enable people to survive and in many cases make a complete recovery, dementia remains a progressive terminal illness. In recent years anti-dementia medication known as acetylcholinesterase inhibitors have been trialled and found to slow down the decline of DAT enabling people to maintain daily functioning for a longer period of time (Doody, Geldmacher, Gorden, Perdomo and Pratt 2001; NICE, 2001). The efficacy of these inhibitors is now been reviewed, with NICE issuing draft guidance querying whether there is sufficient evidence to make these medications available to older people (NICE, 2006).

With these medications subject to review, non pharmaceutical interventions take precedence. Psychosocial interventions are being developed with a theoretical
underpinning from a ‘use it or lose it’ hypothesis namely cognitive rehabilitation (Rice, 1997). Clare, Wilson, Carter, Hodges and Adams (2001) demonstrated how gains from individualised cognitive rehabilitation interventions can be maintained over several years, although the authors offered a note of caution as this was a single case study.

Other therapies have either been developed specifically to ameliorate dementia symptomatology such as reminiscence therapy and reality orientation, or are adaptations of already existing therapies such as music therapy and art therapy. The aim of therapies is either to directly alleviate specific symptoms of dementia e.g. influencing disorientation by exercising orientation ability, or to exert an indirect influence e.g. diminish agitated behaviour through non verbal expression such as art work. Evidence for the effectiveness of these psychosocial interventions is still lacking in terms of controlled, randomised studies (Clare, Woods, Moniz-Cook, Orrell, & Spector, 2004; Grasel, Wiltfang & Kornhuber, 2003) however with pharmacological interventions subject to review it is likely that these psychosocial interventions will gain prominence and efficacy studies will prevail.

Thus far evidence for clinicians’ reasons not to disclose appears to support the argument that ‘myths’ of dementia continue to persist in health care (Milne et al., 2000). Despite advances in treatment options, and accuracy of diagnosis and a paucity of evidence to support a risk of depression, clinicians continue not to give information to patients (Meyers, 1997). Yet evidence from the older adults field suggests that the benefits of disclosure are numerous, both practical and moral. Pinner (2000) argues that disclosure facilitates future planning and it may assist in persuading the patient to accept help and
in managing social needs. Legal matters such as power of attorney and ‘living wills’ can be addressed (Rice, 1997), understanding the potential consequences of the disease can be facilitated, such as limitations to one’s capacity to drive safely (Johnson & Bouman, 1997) Finally disclosure of diagnosis suffices carers’ and patients’ wish to know (Marzanski, 2000, Wilkinson & Milne, 2003).

With the literature advocating a sharing of diagnosis (Ahujn & Williams, 2000; Clafftery, 1999; Pinner, 2000 Rice et al., 1997) as well as National Policy promulgating this (Audit Commission, 2000; National Service Framework for Older People, 2001) there is also a growing consensus on how a disclosure should be shared. In summary, it is suggested that the sharing of diagnoses should be considered on an individual basis, with the person with dementia being consulted about their wish to know their diagnosis, prognosis and information about dementia. Pinner (2000) suggests that a disclosure is an evolving process whereby the clinician delivers information at the pace dictated by the patient rather than having a one off meeting. With regards to what is discussed Clafferty (1999) suggests that people should be given ‘the support and knowledge that allows them the dignity to come to terms with their illness and be involved in plans about their current and future health care’ (p.395).

It is notable in these research discussions that little attention has been paid to clinicians’ decision-making processes. Much of the research has focused on the reasons, the risks and benefits, to disclose or not to a patient yet how a clinician actually arrives at a decision to make a disclosure has been neglected. It can be hypothesised from the decisions-making literature that clinicians use a heuristic methodology as very little
guidance exists to make an informed ideal decision. Decision-making models already exist in medicine (Wigton, 1996) education (Heald, 1991) and law (Dhami, 2003), it would therefore be interesting to see how decision-making in disclosure practice is carried out.

4.5 Carers' experiences of disclosure

The findings from the studies so far has focused on the practice of disclosure from the perspective of health care professionals without acknowledging the experiences of carers when receiving a disclosure. Carers play a significant part in the diagnostic and disclosure process as they are more likely to prompt an assessment than the patient (Iliffe, 1997) and are more likely to receive the disclosure than the patient (Cody et al., 2002; Holroyd, Turnbull & Wolf, 2002) or give the diagnosis to the patient (Heal & Husband, 1998). Carers' attitudes towards a diagnosis of dementia being disclosed to their family member as well as their own attitudes regarding information giving have been investigated. An Italian study by Pucci, Belardinelli, Borsetti & Giuliani (2003) found 60.6% of carers not wanting the person for whom they cared to be fully informed, justifying this decision with concerns of an onset or worsening of depressive symptoms as well as a cultural consideration as dementia is considered highly stigmatizing in Italy. Interestingly, stigma emerged as a significant issue from comparison studies of early dementia care in eight European countries where it emerged as an important influence on delays in recognition and diagnosis by primary care workers. In Spain and Portugal avoidance of the dementia label is related to resources, since it tends to precludes access to nursing home care (Vermooij et al., 2005).
A widely quoted Irish study by Maguire, Kirby, Coen, Coakley, Lawlor and O’Neil (1996) found that only 17% of family members reported that the patient should be told their diagnosis yet 71% of these family members would want to be told if they themselves had develop Alzheimer’s disease. More recent research has found 72% (n=57) (Holroyd, Turnbull & Wolf, 2002) and 58% (n=73) (Heal & Husband, 1998) of carers expressing a wish for the patient to be told. This apparent increase in carers favouring the patient knowing their diagnosis could be viewed as a significant shift in carers’ attitudes to disclosure. However these increases may be due to methodological issues such as study design.

4.6 Patients’ experiences

The patient’s experience has only recently begun to be investigated although it remains under researched (Bamford, Lamont, Eccles, Robinson, May & Bond, 2004, Pearce, Clare & Pistrang, 2002). Marzanski (2000) conducted a survey of patients with early dementia asking their opinions on what they thought was wrong with them, whether and what they had been told by their doctors and what they would like to know about their illness. Interestingly, none of the participants used the term ‘dementia’ to describe what was wrong with them, rather using ‘memory problems’ as a description or giving implausible explanations or denying any knowledge of the cause. The information given to patients varied from reassurance to allegedly inaccurate explanations such as a reaction to bereavement. 66% reported that nobody had talked to them about their illness yet the majority wanted to know what was wrong with them and to access more information. There were methodological limitations to this study namely, a small sample (n=30), with verbal reports based on declarations from cognitively impaired patients,
and the author conceded that there was no opportunity to objectively verify their statements with carers and other healthcare workers. However, the strength of the study is that 70% of patients clearly declared they would like to know more about their illness.

In terms of the emotional impact on receiving the disclosure of a dementia diagnosis studies have found a wide spectrum of reactions from shock and anger (Vemooij-Dassen, Derksen, Scheltens, & Moniz-Cook, 2006) to perceiving the diagnosis as helping to understand the condition (Pearce, Clare & Pistrang, 2002). Husband (1999) reported findings from three patients who were referred for cognitive behavioural therapy following their diagnosis of dementia and found that they were preoccupied with the effects of the diagnosis on self esteem and personhood, rather than feeling depressed and hopeless. In an attempt to explain this variation in individuals’ reactions to a disclosure, Pratt & Wilkinson (2003) based on their findings of ‘tell me the truth study’ for the Mental Health Foundation, developed a psychosocial model to account for individuals’ experiences following a disclosure of a dementia diagnosis (see figure 1).

They argue that the social context needs to be taken into account as well as the individual psychological reaction when considering a disclosure and subsequent work with the individual. The social context includes attitudes and approaches of medical staff, access to information, and the availability of formal and informal support. These factors will interact with the individual’s psychological reactions and will produce varied outcomes dependent upon the point of intersection.
Figure 1

*A psychosocial model of understanding the experience of receiving a diagnosis of dementia (Pratt & Wilkinson, 2003)*

An individual’s experience can be located in any of the ‘quadrants’ as a function of the combined effect of social context, alongside individual response. For example, negative professional attitudes combined with a patient’s wish to know the diagnosis will increase distress for the patient whereas positive professional attitudes combined with a patient’s wish to know will maximise positive coping strategies. Pratt & Wilkinson (2003) argue that the model offers a number of challenges to disclosure practice as it asks medical professionals to examine the ways in which they contribute to distress, namely that practitioners need to see themselves as agents within this social context who can cause distress or facilitation.
4.7 Disclosure practice of ID clinicians

As this discussion has demonstrated there is considerable body of literature on the issue of disclosure of dementia diagnosis in the general population for clinicians, carers and patients. By contrast there is a paucity of research into disclosure of a dementia diagnosis within ID field, although Doswell & Casey (2005) argue that given the older adult research into disclosure practice, ID clinicians may experience similar dilemmas. Research relating to disclosure practices has focused predominantly on disclosure to parents of their child's intellectual disability.

Researchers have explored the parental experience rather than the clinicians’ but similar issues to dementia disclosure would appear to arise. Hatton, Akram, Robertson, Shah and Emerson (2003) reported studies showing that in the UK families there are relatively low levels of parental satisfaction with the disclosure of a child's ID (Pearson, Simms, Ainsworth, & Hill, 1998; Quine & Pahl, 1987; Sloper & Turner, 1993a; Turner & Sloper, 1992). These studies highlighted the practical and emotional aspects to a disclosure with increased satisfaction reported when enough time was given for the consultation, the offering of emotional support and talking about the child in a valued way as well as conducting the disclosure in a professional manner, allowing the parents to ask questions and helping families access financial and support services. Hatton et al., (2003) conducted a study into the experiences of South Asian families of receiving a diagnosis and found that good practice in disclosure was less common for families in their study then aforementioned previous studies which were with white families. Poor practice was attributed to the length of time taken to receive a diagnosis compared to white families and language issues, for example two-thirds of disclosures were in
English, despite this being the preferred language of very few parents. Hatton et al., (2003) also commented that parents in the study reported that the disclosure process had a significant impact on their understanding of the child’s condition, and as a consequence, the emotional acceptance of their child. They concluded poorly conducted disclosure and lack of post-disclosure support can result in long term problems with family acceptance of the child, the uptake of benefits, parental awareness and use of family support services.

It can be hypothesised that parents may encounter more than one major disclosure episode whilst caring for their offspring, the first being the diagnosis of the intellectual disability and the second could be a health related condition such as cancer or an age related condition such as dementia. Certainly, Faust (2003) reported parents experiencing a ‘double whammy’ resulting from their children being diagnosed with a mental health problem additional to their ID. It could also be hypothesised that carers of PWID experiences of receiving a disclosure of dementia may differ depending on whether they are a family member or a paid carer.

4.8 Section summary

Despite studies demonstrating positive benefits of disclosing a diagnosis of dementia to a patient, namely facilitates future planning, and may assist a patient accepting help and managing social needs, clinicians are often reluctant to disclose a diagnosis. Studies have identified a range of reasons underpinning this reluctance, from patients poor insight, lack of effective interventions, may cause undue emotional upset, exacerbating a risk of depression as well as perceiving the diagnosis to be stigmatising. Further studies
argue that there is paucity of evidence to support a risk of depression, rather patients felt relief and validation for finding an explanation to their problems plus there have been significant advances in pharmacological and psychosocial interventions providing options to ameliorate the symptoms of dementia. Psychosocial models have been proposed to explain the wide variation in patient reactions to a disclosure and request professionals consider the social context in which a disclosure is made. Finally the disclosure practice of ID clinicians has focused predominantly on disclosure to parents of their child's ID. It is hypothesised that given the extensive research disclosure practice in the older adult literature that ID clinicians may encounter similar dilemmas.
5. Conclusion

This review has attempted to highlight the current issues in meeting the needs of ageing adults with intellectual disabilities as well as older adults from the general population. In the ID field there has been significant development in understanding the course of ageing in this cohort as well as increased knowledge about the onset and progression of conditions such as dementia in PWID, particularly those with Down’s syndrome. Nonetheless there is still an urgent need to reach diagnostic consensus for PWID with dementia, both with and without Down’s syndrome, plus research to develop standardised assessment tools and protocols to provide accurate and timely diagnosis. This research is hampered by methodological issues such as poorly designed studies and small sample sizes. The existence of pre-existing cognitive impairments and conditions arising from the sequelae of the person’s intellectual disability also make assessments difficult.

The current fragmentation of service provision for this client group was also discussed and recommendations were made to bring increased multi agency working and increased funding for services to meet the changing demography of this client group. Commissioners and providers require greater knowledge and understanding of this cohort and their needs to ensure they have the resources required to plan and deliver effective and high quality services.

It was evident in the general population that assessment of dementia, namely through the memory clinic model, and clinical practice were well developed with clear guidelines on how to assess for dementia, diagnosis it and then disclose to a patient and their carer.
However, some researchers have called for evaluation of the memory clinic model to establish definitively the benefits for both the patient and the NHS. Dementia care practice has been challenged by the work of Tom Kitwood, who vehemently argues that the reductionistic and deterministic view of dementia can be damaging to the well being of the person with dementia. He argues that a more humane and compassionate approach that acknowledges the uniqueness of the individual and addresses their personhood promotes well being. He has operationalised these psychosocial models of care by developing Dementia Care Mapping thus enabling care provisions to adopt person-centred approaches.

Finally an issue from clinical practice was explored, namely disclosure of a dementia diagnosis and the advantages and disadvantages were discussed. The literature concluded that some clinicians still held beliefs that a disclosure of dementia would be detrimental to the patient/carer despite clear evidence to the contrary and that instead there were practical, moral and emotional benefits that came from disclosure of the diagnosis. Psychosocial models have been developed to explain the variation in individual reactions to receiving a diagnosis and recommendations have been made for clinicians to address the social context as well as the individual psychological reaction when disclosing a diagnosis. It was evident that clinicians in the intellectual disability field needed also to improve their disclosure practice however the literature has so far concentrated on paediatric diagnosis rather than dementia and this area remains under-researched.
It is evident from this review that both the ID and the older adult fields have independently advanced the understanding of the neuropathological and psychosocial dimensions of dementia yet remain resolutely separated. There are obvious opportunities to engage in cross cutting dialogue between ID and older adult researchers and share knowledge for example person centred approaches to dementia care. In time a universal approach to ageing may emerge with adaptations for the additional needs arising from living with an ID.
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Empirical Paper

Ageing and Intellectual Disabilities

Clinical psychologists’ experiences of assessing and treating people with intellectual disabilities and dementia
Abstract

It is now widely recognized that people with Down’s syndrome are at an increased risk of developing dementia. Little is known about clinicians’ attitudes and practices in meeting the needs of this group.

Using a dual quantitative and qualitative methodology this study aimed to capture how clinicians specialising in intellectual disabilities (ID) currently proceed when assessing a client with ID for dementia. This study also compared clinical, methodological and ethical issues, particularly the disclosure of dementia diagnosis, of ID clinicians and those reported in the older adult literature.

The results suggest marked variability in practice, assessment methods and explanations given to service users and carers. Overall, this study suggests there need to be urgent changes, both nationally and locally to address shortfalls in service provision. There also needs to be further research into improving reliability and validity of assessment tools and the disclosure practices of clinicians.
Introduction

Changing demography in Intellectual Disabilities

Improvements in standard of living and access to medical treatments have resulted in better health and enhanced longevity for people with intellectual disabilities (PWID) (Hatzidimitriadou & Milne, 2005). According to a recent British report, life expectancy for PWID has increased dramatically from 20 years in 1930 to 70-74 years in 1990 (Foundation for People with Learning Disabilities, 2002). Surviving into old age places older people with intellectual disabilities at greater risk of a range of physical problems, such as arthritis, rheumatic illness, cardiac and pulmonary conditions and a decline in hearing, sight and mobility (Evenhuis, 1999). Age related conditions impact earlier on PWID than the general population due to factors related to specific syndromes of ID such as Down’s syndrome, associated developmental disabilities as well as lifestyle and environmental issues (Evenhuis, Henderson, Beange, Lennox and Chicoine, 2001).

Down’s syndrome and dementia

Interest in the ageing process of PWID is not new and was first promulgated due to the discovery of the high risk of dementia of the Alzheimer’s type (DAT) in people with Down’s Syndrome (Zigman et al., 2004). Virtually all adults with Down’s syndrome over the age of 35-40 years who have been autopsied show the key neuropathological changes characteristic of DAT (Wisniewski, Wisniewski & Wen, 1985). Approximately 50-60% of these individuals develop symptoms indicative of DAT by the time they reach 60-70 years (Zigman, Schupf, Haveman & Silverman, 1997). This phenomenon
has been explained with reference to biological processes associated with DAT and also with Down's syndrome (see Schupf, 2002).

The manifestation of dementia symptomology appears to be equally severe in people with Down's syndrome as in the general population. However, the progression of DAT in people with Down's syndrome is accelerated, often with a briefer duration of 2-8 years and the end stage being reached much sooner than among those in the general population affected by the disease (Prasher & Krishman, 1993).

**Assessment of dementia in PWID**

In recent years, a consensus has emerged on the model of best practice when assessing dementia in PWID, namely a prospective tripartite approach (Burt & Aylward, 2000). Accordingly, a baseline of premorbid functioning should be established by age 35, prior to any potential onset of dementia symptomology, with yearly follow ups (Aylward, Burt, Thorpe, Lai & Dalton, 1997; Burt *et al.*, 2000). Secondly, when deterioration is indicated a careful and accurate diagnosis of dementia is required whereby all other possible explanations for the deterioration should be ruled out. Thirdly, following diagnosis the client and those who care for him need to receive a service that is titrated to their nature and level of need (Aylward, *et al.*, 1997).

The IASSID recommendations have enabled models of good practice to emerge, with a consensus being reached by UK researchers and practitioners on guidelines for working with this group as well as materials being produced to help carers and professionals alike deliver appropriate services (Dodd, Turk & Christmas, 2002; Janicki & Dalton, 1999;
Kerr & Wilson, 2001). These guidelines argue that four dimensions are requisite if the rights and needs of people with ID and dementia are to be met, including adopting a workable philosophy of care such as person centered approaches; practices including the use of standardised assessment tools and staff training; coordinating diverse systems together and agreeing who has the responsibility for this client group, ID services or generic older adult services; and finally, promoting relevant research to advance the current knowledge base (Wilkinson & Janicki, 2002).

Service Provision for Ageing PWID

Recent policy reviews in the UK have advocated that policy-makers, commissioners and providers reorganise, reform and develop services to ensure that health and social care services meet the needs of older people with ID (Department of Health, 2001a; Foundation for People with Learning Disabilities, 2003; Scottish Executive, 2000). However, there seems to be a gap between what is recommended and what is implemented, with highly variable local practice (Jokinen, 2005).

Hatzidimitriadou & Milne (2005) argue that in the UK current service delivery is characterised by fragmentation, limited resources and specialist care and inadequate training for staff. Problems identified in other studies include; widespread confusion about which agencies and professionals were responsible for providing services for this client group (Fitzgerald, 1998); lack of investment in specialist services for this client group, limited access to psychiatric and general health care services and low expectations of users by staff (Aspray, Francis, Tryer & Quilliam, 1999; Dagnan & Ruddick, 1997; Duff, Houghton, Scheepers, 2000; Hassiotis, Barron & O’Hora, 2000).
These difficulties in providing co-ordinated and responsive services result in care decisions based on available resources rather than a coherent strategy and are often dictated by a crisis, resulting in rapid decline and in some cases premature death (Wilkinson, Kerr, Cunningham & Rae, 2004; Thompson and Wright, 2001). These studies largely concentrate on the structural dimensions of care but seem to neglect the psychosocial aspects of dementia care. This is not surprising as evaluating ID dementia care is still embryonic. Measuring psychosocial dimensions of care has been extensively researched in the older adult literature and Dementia Care Mapping (DCM) is an example, designed to promote an understanding of dementia care from the viewpoint of the person with dementia (Kitwood, 1997). DCM is grounded within person-centered approaches to dementia care and records both the quality and quantity of staff behaviors over a care day as well as assessing the well being of the client through systematic observation and recording. These findings are then shared with the staff to raise awareness of care practices and their effects on people in their care. DCM has proved to be a valid measure for frontline staff as well as those commissioning care, providing detailed information on quality of life in dementia care (Brooker, 2005). DCM offers a starting point in considering the psychosocial dimensions of care for this client group but to date seems to have had little impact on ID services.

Service provision for older adults

As there is a paucity of literature on service provision and delivery in the ID field it is useful to draw on research and practice from the older adult literature. Service provision for people with suspected and diagnosed dementia in the general population is primarily delivered through primary care and specialist services such as memory clinics which are
situated within old age psychiatry services (Department of Health, 2001b). The ethos of such clinics is to provide early diagnosis as well as advice on how to manage the condition (Foreman, Gardner & Davies, 2004). Passmore & Craig (2004) identified the benefits of early diagnosis as providing access to treatments, planning of future care, helping the family to come to terms with prognosis and to help understand changes in memory, behaviour and personality. Memory clinics are typically multi-disciplinary and usually a patient will see representatives from psychology, psychiatry and sometimes nursing and social work in a single appointment.

Attempts have been made to bring the memory clinic model to the ID population namely in Canada (McCreary, Fotheringham, Holden, Ouellette-Kuntz & Robertson, 1993), the USA (Chicoine, McGuire & Rubin, 1999) and the UK (Hassiotis, Strydom Allen & Walker, 2003). The UK authors concluded that the framework of a memory clinic was useful but without additional funding difficult to implement long term.

Clinical Issues in Older Adult Services

An issue that has been debated extensively in the older adult literature is how clinicians disclose a diagnosis of dementia. The NSF for older people (Department of Health, 2001) has specifically identified the importance of early diagnosis of dementia in enabling people and their families to respond effectively and that this should always involve explaining the diagnosis to the older person and any carers.

With the development of new drug regimes that can slow down the progression of the early stages of dementia, the disclosure of diagnosis has gained prominence as clinicians
are required to seek consent before commencing drug treatment. The responsibility of disclosure can fall to GPs or specialists in secondary and tertiary services. Research on disclosing a diagnosis of dementia has found both perceived positive and negative consequences. For example, research into GPs attitudes towards disclosure identified the following reasons for not disclosing: wariness of misdiagnosis (Cody, Beck, Pope & Shue, 2002; Milne, Woolford, Mason, & Hatzidimitiadou, 2000); inability to offer effective treatments (Milne et al., 2000; Van Gool & Van Crevel, 1996); time constraints (Milne et al., 2000; Olasfsdottir, Skoog & Marcusson, 2000) and stigma (Vemooij-Dassen et al., 2005).

Psychiatrists, geriatricians and mental health clinicians have postulated similar reasons and also have concerns such as patients' poor cognitive insight (Johnson, Bouman, & Pinner 2000; Rice, Warner, Tye & Bayer, 1997), the risk of causing distress as a result of receiving the diagnosis which may in turn bring an onset or exacerbation of depression, induce feelings of hopelessness and a catastrophic reaction (Claffery, 1999; Johnson, Bouman & Pinner, 2000; Keightley & Mitchell, 2004) or even suicide (Rhode, Peskind and Raskind, 1995). However, the combination of advances in medication with psychosocial interventions, availability of clear and accurate diagnostic criteria in ICD 10 and DSM IV and a paucity of evidence to support a risk of depression indicates that clinicians' reasons for disclosing may well be unfounded. Evidence suggests that the benefits of disclosure are numerous, both practical and moral. Pinner (2000) argues that disclosure facilitates future planning and it may assist in persuading the patient to accept help and in managing social needs. Legal matters such as 'power of attorney' and 'living wills' can be addressed, understanding the potential consequences of the disease can be
facilitated such as the limitations of one's capacity to drive safely (Johnson & Bouman, 1997). Finally disclosure addresses carers' and patients' professed wishes to know (Marzanski, 2000; Wilkinson & Milne, 2003).

In understanding the subjective experience of people with dementia a number of models have attempted to describe, explain and conceptualise the experience of people with dementia (Keady & Nolan, 1995; Harris & Stein, 1999; Clare, 2002). Pratt and Wilkinson (2003) propose a model which takes account of both individual responses and the social context to understand the experience of people with dementia (see figure 1). The model proposes that individual experience can be located in any of these 'quadrants' as a function of the combined effect of social context and individual response.

**Figure 1**

*A psychosocial model of understanding the experience of receiving a diagnosis of dementia (Pratt & Wilkinson, 2003)*

Ability and desire to know diagnosis (high)  

Distress  

Maximising coping strategies  

Social context (negative)  

Detachment  

Decline and denial  

Ability and desire to know diagnosis (low)
With regards to clinicians’ disclosure practice in the ID field, little is known with respect to dementia. It can be hypothesized that there will be a reluctance to disclose a diagnosis of dementia to PWID given clinicians’ reported reluctance to disclose to people with dementia in the general population (Doswell and Casey, 2005).

Research Questions

In view of the picture of fragmented and under-funded service provision it seems timely to investigate what clinicians are currently doing to meet the needs of ageing clients with ID, specifically those with Down’s syndrome and dementia. This study aims to obtain a snapshot of ID services and ask the following questions:

1. How are clinical psychologists specialising in ID currently proceeding when assessing a client with ID for dementia?

2. What are their experiences of discussing dementia with PWID?

3. Are there similarities and differences in the clinical, methodological and ethical issues encountered by those working with older adults and those working with ageing adults with ID regarding dementia assessment?
4.3 Psychiatrists and mental health professionals’ disclosure practice

Rae, McIntosh and Colles (2001) reported that disclosing a diagnosis was rated as the fifth most difficult aspect of dementia management by GPs but these difficulties have also been found amongst clinicians in memory clinics and old age psychiatry services (Gilliard & Gwilliam, 1996; Johnson, Bouman & Pinner, 2000). A recent qualitative study by Keightley & Mitchell (2004) with mental health professionals, concluded that the main influence on professionals’ disclosure practice was lack of certainty about whether the person with dementia would want to know their diagnosis or not, which was, in turn influenced by professional’s perceptions of dementia and their sense of the impact of knowing. The participants reported a sense of hopelessness and helplessness that the authors linked to the professionals perception of dementia as something ‘worse than death’ with an inevitable course. With regard to psychiatrists who are primarily responsible for disclosure in memory clinics and old age psychiatric services, Clafferty, Brown and McCabe (1998) found that only 44% of their sample informed their patients of their diagnosis of dementia. One criticism of this study is that Clafferty et al., (1998) sent a questionnaire to all consultant psychiatrists in Scotland asking them to comment on their disclosure practices for a range of psychiatric disorders. Therefore many of the participants would not have encountered the scenario of disclosing a dementia diagnosis.

The discussion so far has focused on professionals reasons to disclose yet few studies have explored how disclosing a dementia diagnosis impacts on the clinician psychologically. This is surprising given the extensive cancer literature on physicians’ experiences of breaking bad news, particularly how it can be stressful, even after completing a disclosure encounter with the patient severally hours earlier, and how
appears to effect junior and inexperienced physicians more (Ptacek, Ptacek & Ellison, 2001). It could be hypothesised that the dementia field is embryonic in considering these issues and in time researchers will move from the risks and benefits of a disclosure to the psychological impact on delivering and receiving a dementia diagnosis.

4.4 Risks and benefits of disclosing a dementia diagnosis

The possible risks and benefits of a disclosure perceived by clinicians have been highlighted in the aforementioned studies with GPs and mental health professionals, focusing on the advantages and disadvantages of disclosing. One reported disadvantage is the possible risk of causing emotional distress that may manifest from receiving the diagnosis and may bring an onset or exacerbation of depression, induce feelings of hopelessness, and a catastrophic reaction (Ahujun & Williams, 2000; Clafferty, 1999; Keightley & Mitchell, 2004) or even suicide (Rohde, Peskind & Raskind, 1995). Studies of patients’ reactions following disclosure found a range of emotions were experienced including shock, anger and fear as well as negative effects on self confidence and esteem (Husband, 1999; Pearce, Clare & Pistrang, 2002). In contrast Pratt and Wilkinson (2001) argue that a disclosure can in fact be a relief and validation rather than a distressing experiencing as the individual has an explanation for the changes that they had recognised in themselves.

Clinicians have also described patient’s poor insight into their condition as a reason for not disclosing (Rao, 1997) with Pinner (2000) stating that in the late stages of the disease the truth will neither benefit nor harm and disclosure is merely futile. Rice (1997) surveyed old age psychiatry consultants and found 38% ‘nearly always’ informed mildly
demented patients but in the case of moderate and severe dementia only 13% and 6% respectively discussed the diagnosis with patients. There were similar findings in a survey of geriatricians but geriatricians appeared to inform patients with mild dementia of their diagnosis more frequently than their carers (Rice, Warner, Tye and Bayer, 1997). What is interesting about these findings is the possible inconsistency between clinicians arguing that a disclosure may have a profound negative impact on the patients mental health yet also arguing that a patient may have poor insight and would be unable to retain and comprehend the explanation. One may wonder if a patient cannot comprehend and remember a disclosure how they are supposed to become depressed.

Another major finding regarding clinicians’ reasons for not disclosing dementia concerns the idea that there is little that can be offered in terms of effective treatment (Clafferty, 1999; Downs, Cribbens, Rae, Cook & Woods, 2002; Milne et al., 2000;). Unlike cancer where significant advances have been made to enable people to survive and in many cases make a complete recovery, dementia remains a progressive terminal illness. In recent years anti-dementia medication known as acetylcholinesterase inhibitors have been trialled and found to slow down the decline of DAT enabling people to maintain daily functioning for a longer period of time (Doody, Geldmacher, Gorden, Perdomo and Pratt 2001; NICE, 2001). The efficacy of these inhibitors is now been reviewed, with NICE issuing draft guidance querying whether there is sufficient evidence to make these medications available to older people (NICE, 2006).

With these medications subject to review, non pharmaceutical interventions take precedence. Psychosocial interventions are being developed with a theoretical
underpinning from a ‘use it or lose it’ hypothesis namely cognitive rehabilitation (Rice, 1997). Clare, Wilson, Carter, Hodges and Adams (2001) demonstrated how gains from individualised cognitive rehabilitation interventions can be maintained over several years, although the authors offered a note of caution as this was a single case study.

Other therapies have either been developed specifically to ameliorate dementia symptomology such as reminiscence therapy and reality orientation, or are adaptations of already existing therapies such as music therapy and art therapy. The aim of therapies is either to directly alleviate specific symptoms of dementia e.g. influencing disorientation by exercising orientation ability, or to exert an indirect influence e.g. diminish agitated behaviour through non verbal expression such as art work. Evidence for the effectiveness of these psychosocial interventions is still lacking in terms of controlled, randomised studies (Clare, Woods, Moniz-Cook, Orrell, & Spector, 2004; Grasel, Wiltfang & Kornhuber, 2003) however with pharmacological interventions subject to review it is likely that these psychosocial interventions will gain prominence and efficacy studies will prevail.

Thus far evidence for clinicians’ reasons not to disclose appears to support the argument that ‘myths’ of dementia continue to persist in health care (Milne et al., 2000). Despite advances in treatment options, and accuracy of diagnosis and a paucity of evidence to support a risk of depression, clinicians continue not to give information to patients (Meyers, 1997). Yet evidence from the older adults field suggests that the benefits of disclosure are numerous, both practical and moral. Pinner (2000) argues that disclosure facilitates future planning and it may assist in persuading the patient to accept help and
in managing social needs. Legal matters such as power of attorney and ‘living wills’ can be addressed (Rice, 1997), understanding the potential consequences of the disease can be facilitated, such as limitations to one’s capacity to drive safely (Johnson & Bouman, 1997) Finally disclosure of diagnosis suffices carers’ and patients’ wish to know (Marzanski, 2000, Wilkinson & Milne, 2003).

With the literature advocating a sharing of diagnosis (Ahuja & Williams, 2000; Clafferty, 1999; Pinner, 2000 Rice et al., 1997) as well as National Policy promulgating this (Audit Commission, 2000; National Service Framework for Older People, 2001) there is also a growing consensus on how a disclosure should be shared. In summary, it is suggested that the sharing of diagnoses should be considered on an individual basis, with the person with dementia being consulted about their wish to know their diagnosis, prognosis and information about dementia. Pinner (2000) suggests that a disclosure is an evolving process whereby the clinician delivers information at the pace dictated by the patient rather than having a one off meeting. With regards to what is discussed Clafferty (1999) suggests that people should be given ‘the support and knowledge that allows them the dignity to come to terms with their illness and be involved in plans about their current and future health care’ (p.395).

It is notable in these research discussions that little attention has been paid to clinicians’ decision-making processes. Much of the research has focused on the reasons, the risks and benefits, to disclose or not to a patient yet how a clinician actually arrives at a decision to make a disclosure has been neglected. It can be hypothesised from the decisions-making literature that clinicians use a heuristic methodology as very little
guidance exists to make an informed ideal decision. Decision-making models already exist in medicine (Wigton, 1996) education (Heald, 1991) and law (Dhami, 2003), it would therefore be interesting to see how decision-making in disclosure practice is carried out.

4.5 Carers’ experiences of disclosure

The findings from the studies so far has focused on the practice of disclosure from the perspective of health care professionals without acknowledging the experiences of carers when receiving a disclosure. Carers play a significant part in the diagnostic and disclosure process as they are more likely to prompt an assessment than the patient (Iliffe, 1997) and are more likely to receive the disclosure than the patient (Cody et al., 2002; Holroyd, Turnbull & Wolf, 2002) or give the diagnosis to the patient (Heal & Husband, 1998). Carers’ attitudes towards a diagnosis of dementia being disclosed to their family member as well as their own attitudes regarding information giving have been investigated. An Italian study by Pucci, Belardinelli, Borsetti & Giuliani (2003) found 60.6% of carers not wanting the person for whom they cared to be fully informed, justifying this decision with concerns of an onset or worsening of depressive symptoms as well as a cultural consideration as dementia is considered highly stigmatizing in Italy. Interestingly, stigma emerged as a significant issue from comparison studies of early dementia care in eight European countries where it emerged as an important influence on delays in recognition and diagnosis by primary care workers. In Spain and Portugal avoidance of the dementia label is related to resources, since it tends to precludes access to nursing home care (Vemooij et al., 2005).
A widely quoted Irish study by Maguire, Kirby, Coen, Coakley, Lawlor and O'Neil (1996) found that only 17% of family members reported that the patient should be told their diagnosis yet 71% of these family members would want to be told if they themselves had develop Alzheimer's disease. More recent research has found 72% (n=57) (Holroyd, Turnbull & Wolf, 2002) and 58% (n=73) (Heal & Husband, 1998) of carers expressing a wish for the patient to be told. This apparent increase in carers favouring the patient knowing their diagnosis could be viewed as a significant shift in carers’ attitudes to disclosure. However these increases may be due to methodological issues such as study design.

4.6 Patients’ experiences

The patient’s experience has only recently begun to be investigated although it remains under researched (Bamford, Lamont, Eccles, Robinson, May & Bond, 2004, Pearce, Clare & Pistrang, 2002). Marzanski (2000) conducted a survey of patients with early dementia asking their opinions on what they thought was wrong with them, whether and what they had been told by their doctors and what they would like to know about their illness. Interestingly, none of the participants used the term ‘dementia’ to describe what was wrong with them, rather using ‘memory problems’ as a description or giving implausible explanations or denying any knowledge of the cause. The information given to patients varied from reassurance to allegedly inaccurate explanations such as a reaction to bereavement. 66% reported that nobody had talked to them about their illness yet the majority wanted to know what was wrong with them and to access more information. There were methodological limitations to this study namely, a small sample (n=30), with verbal reports based on declarations from cognitively impaired patients,
and the author conceded that there was no opportunity to objectively verify their statements with carers and other healthcare workers. However, the strength of the study is that 70% of patients clearly declared they would like to know more about their illness.

In terms of the emotional impact on receiving the disclosure of a dementia diagnosis studies have found a wide spectrum of reactions from shock and anger (Vernooij-Dassen, Derksen, Scheltens, & Moniz-Cook, 2006) to perceiving the diagnosis as helping to understand the condition (Pearce, Clare & Pistrang, 2002). Husband (1999) reported findings from three patients who were referred for cognitive behavioural therapy following their diagnosis of dementia and found that they were preoccupied with the effects of the diagnosis on self esteem and personhood, rather than feeling depressed and hopeless. In an attempt to explain this variation in individuals’ reactions to a disclosure, Pratt & Wilkinson (2003) based on their findings of ‘tell me the truth study’ for the Mental Health Foundation, developed a psychosocial model to account for individuals’ experiences following a disclosure of a dementia diagnosis (see figure 1).

They argue that the social context needs to be taken into account as well as the individual psychological reaction when considering a disclosure and subsequent work with the individual. The social context includes attitudes and approaches of medical staff, access to information, and the availability of formal and informal support. These factors will interact with the individual’s psychological reactions and will produce varied outcomes dependent upon the point of intersection.
An individual's experience can be located in any of the 'quadrants' as a function of the combined effect of social context, alongside individual response. For example negative professional attitudes combined with a patient's wish to know the diagnosis will increase distress for the patient whereas positive professional attitudes combined with a patient's wish to know will maximise positive coping strategies. Pratt & Wilkinson (2003) argue that the model offers a number of challenges to disclosure practice as it asks medical professionals to examine the ways in which they contribute to distress, namely that practitioners need to see themselves as agents within this social context who can cause distress or facilitation.
4.7 Disclosure practice of ID clinicians

As this discussion has demonstrated there is considerable body of literature on the issue of disclosure of dementia diagnosis in the general population for clinicians, carers and patients. By contrast there is a paucity of research into disclosure of a dementia diagnosis within ID field, although Doswell & Casey (2005) argue that given the older adult research into disclosure practice, ID clinicians may experience similar dilemmas. Research relating to disclosure practices has focused predominantly on disclosure to parents of their child’s intellectual disability.

Researchers have explored the parental experience rather than the clinicians’ but similar issues to dementia disclosure would appear to arise. Hatton, Akram, Robertson, Shah and Emerson (2003) reported studies showing that in the UK families there are relatively low levels of parental satisfaction with the disclosure of a child’s ID (Pearson, Simms, Ainsworth, & Hill, 1998; Quine & Pahl, 1987; Sloper & Turner, 1993a; Turner & Sloper, 1992). These studies highlighted the practical and emotional aspects to a disclosure with increased satisfaction reported when enough time was given for the consultation, the offering of emotional support and talking about the child in a valued way as well as conducting the disclosure in a professional manner, allowing the parents to ask questions and helping families access financial and support services. Hatton et al., (2003) conducted a study into the experiences of South Asian families of receiving a diagnosis and found that good practice in disclosure was less common for families in their study then aforementioned previous studies which were with white families. Poor practice was attributed to the length of time taken to receive a diagnosis compared to white families and language issues, for example two-thirds of disclosures were in
English, despite this being the preferred language of very few parents. Hatton et al., (2003) also commented that parents in the study reported that the disclosure process had a significant impact on their understanding of the child's condition, and as a consequence, the emotional acceptance of their child. They concluded poorly conducted disclosure and lack of post-disclosure support can result in long term problems with family acceptance of the child, the uptake of benefits, parental awareness and use of family support services. 

It can be hypothesised that parents may encounter more than one major disclosure episode whilst caring for their offspring, the first being the diagnosis of the intellectual disability and the second could be a health related condition such as cancer or an age related condition such as dementia. Certainly, Faust (2003) reported parents experiencing a 'double whammy' resulting from their children being diagnosed with a mental health problem additional to their ID. It could also be hypothesised that carers of PWID experiences of receiving a disclosure of dementia may differ depending on whether they are a family member or a paid carer.

4.8 Section summary

Despite studies demonstrating positive benefits of disclosing a diagnosis of dementia to a patient, namely facilitates future planning, and may assist a patient accepting help and managing social needs, clinicians are often reluctant to disclose a diagnosis. Studies have identified a range of reasons underpinning this reluctance, from patients poor insight, lack of effective interventions, may cause undue emotional upset, exacerbating a risk of depression as well as perceiving the diagnosis to be stigmatising. Further studies
argue that there is paucity of evidence to support a risk of depression, rather patients felt relief and validation for finding an explanation to their problems plus there have been significant advances in pharmacological and psychosocial interventions providing options to ameliorate the symptoms of dementia. Psychosocial models have been proposed to explain the wide variation in patient reactions to a disclosure and request professionals consider the social context in which a disclosure is made. Finally the disclosure practice of ID clinicians has focused predominantly on disclosure to parents of their child's ID. It is hypothesised that given the extensive research disclosure practice in the older adult literature that ID clinicians may encounter similar dilemmas.
5. Conclusion

This review has attempted to highlight the current issues in meeting the needs of ageing adults with intellectual disabilities as well as older adults from the general population. In the ID field there has been significant development in understanding the course of ageing in this cohort as well as increased knowledge about the onset and progression of conditions such as dementia in PWID, particularly those with Down’s syndrome. Nonetheless there is still an urgent need to reach diagnostic consensus for PWID with dementia, both with and without Down’s syndrome, plus research to develop standardised assessment tools and protocols to provide accurate and timely diagnosis. This research is hampered by methodological issues such as poorly designed studies and small sample sizes. The existence of pre-existing cognitive impairments and conditions arising from the sequelae of the person’s intellectual disability also make assessments difficult.

The current fragmentation of service provision for this client group was also discussed and recommendations were made to bring increased multi agency working and increased funding for services to meet the changing demography of this client group. Commissioners and providers require greater knowledge and understanding of this cohort and their needs to ensure they have the resources required to plan and deliver effective and high quality services.

It was evident in the general population that assessment of dementia, namely through the memory clinic model, and clinical practice were well developed with clear guidelines on how to assess for dementia, diagnosis it and then disclose to a patient and their carer.
However, some researchers have called for evaluation of the memory clinic model to establish definitively the benefits for both the patient and the NHS. Dementia care practice has been challenged by the work of Tom Kitwood, who vehemently argues that the reductionistic and deterministic view of dementia can be damaging to the well being of the person with dementia. He argues that a more humane and compassionate approach that acknowledges the uniqueness of the individual and addresses their personhood promotes well being. He has operationalised these psychosocial models of care by developing Dementia Care Mapping thus enabling care provisions to adopt person-centred approaches.

Finally an issue from clinical practice was explored, namely disclosure of a dementia diagnosis and the advantages and disadvantages were discussed. The literature concluded that some clinicians still held beliefs that a disclosure of dementia would be detrimental to the patient/carer despite clear evidence to the contrary and that instead there were practical, moral and emotional benefits that came from disclosure of the diagnosis. Psychosocial models have been developed to explain the variation in individual reactions to receiving a diagnosis and recommendations have been made for clinicians to address the social context as well as the individual psychological reaction when disclosing a diagnosis. It was evident that clinicians in the intellectual disability field needed also to improve their disclosure practice however the literature has so far concentrated on paediatric diagnosis rather than dementia and this area remains under-researched.
It is evident from this review that both the ID and the older adult fields have independently advanced the understanding of the neuropathological and psychosocial dimensions of dementia yet remain resolutely separated. There are obvious opportunities to engage in cross cutting dialogue between ID and older adult researchers and share knowledge for example person centred approaches to dementia care. In time a universal approach to ageing may emerge with adaptations for the additional needs arising from living with an ID.
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Empirical Paper

*Ageing and Intellectual Disabilities*

Clinical psychologists’ experiences of assessing and treating people with intellectual disabilities and dementia
Abstract

It is now widely recognized that people with Down's syndrome are at an increased risk of developing dementia. Little is known about clinicians' attitudes and practices in meeting the needs of this group.

Using a dual quantitative and qualitative methodology this study aimed to capture how clinicians specialising in intellectual disabilities (ID) currently proceed when assessing a client with ID for dementia. This study also compared clinical, methodological and ethical issues, particularly the disclosure of dementia diagnosis, of ID clinicians and those reported in the older adult literature.

The results suggest marked variability in practice, assessment methods and explanations given to service users and carers. Overall, this study suggests there need to be urgent changes, both nationally and locally to address shortfalls in service provision. There also needs to be further research into improving reliability and validity of assessment tools and the disclosure practices of clinicians.
Introduction

Changing demography in Intellectual Disabilities

Improvements in standard of living and access to medical treatments have resulted in better health and enhanced longevity for people with intellectual disabilities (PWID) (Hatzidimitriadou & Milne, 2005). According to a recent British report, life expectancy for PWID has increased dramatically from 20 years in 1930 to 70-74 years in 1990 (Foundation for People with Learning Disabilities, 2002). Surviving into old age places older people with intellectual disabilities at greater risk of a range of physical problems, such as arthritis, rheumatic illness, cardiac and pulmonary conditions and a decline in hearing, sight and mobility (Evenhuis, 1999). Age related conditions impact earlier on PWID than the general population due to factors related to specific syndromes of ID such as Down’s syndrome, associated developmental disabilities as well as lifestyle and environmental issues (Evenhuis, Henderson, Beange, Lennox and Chicoine, 2001).

Down’s syndrome and dementia

Interest in the ageing process of PWID is not new and was first promulgated due to the discovery of the high risk of dementia of the Alzheimer’s type (DAT) in people with Down’s Syndrome (Zigman et al., 2004). Virtually all adults with Down’s syndrome over the age of 35-40 years who have been autopsied show the key neuropathological changes characteristic of DAT (Wisniewski, Wisniewski & Wen, 1985). Approximately 50-60% of these individuals develop symptoms indicative of DAT by the time they reach 60-70 years (Zigman, Schupf, Haveman & Silverman, 1997). This phenomenon...
has been explained with reference to biological processes associated with DAT and also with Down’s syndrome (see Schupf, 2002).

The manifestation of dementia symptomology appears to be equally severe in people with Down’s syndrome as in the general population. However, the progression of DAT in people with Down’s syndrome is accelerated, often with a briefer duration of 2-8 years and the end stage being reached much sooner than among those in the general population affected by the disease (Prasher & Krishman, 1993).

Assessment of dementia in PWID

In recent years, a consensus has emerged on the model of best practice when assessing dementia in PWID, namely a prospective tripartite approach (Burt & Aylward, 2000). Accordingly, a baseline of premorbid functioning should be established by age 35, prior to any potential onset of dementia symptomology, with yearly follow ups (Aylward, Burt, Thorpe, Lai & Dalton, 1997; Burt et al., 2000). Secondly, when deterioration is indicated a careful and accurate diagnosis of dementia is required whereby all other possible explanations for the deterioration should be ruled out. Thirdly, following diagnosis the client and those who care for him need to receive a service that is titrated to their nature and level of need (Aylward, et al., 1997).

The IASSID recommendations have enabled models of good practice to emerge, with a consensus being reached by UK researchers and practitioners on guidelines for working with this group as well as materials being produced to help carers and professionals alike deliver appropriate services (Dodd, Turk & Christmas, 2002; Janicki & Dalton, 1999;
Kerr & Wilson, 2001). These guidelines argue that four dimensions are requisite if the rights and needs of people with ID and dementia are to be met, including adopting a workable philosophy of care such as person centered approaches; practices including the use of standardised assessment tools and staff training; coordinating diverse systems together and agreeing who has the responsibility for this client group, ID services or generic older adult services; and finally, promoting relevant research to advance the current knowledge base (Wilkinson & Janicki, 2002).

*Service Provision for Ageing PWID*

Recent policy reviews in the UK have advocated that policy-makers, commissioners and providers reorganise, reform and develop services to ensure that health and social care services meet the needs of older people with ID (Department of Health, 2001a; Foundation for People with Learning Disabilities, 2003; Scottish Executive, 2000). However, there seems to be a gap between what is recommended and what is implemented, with highly variable local practice (Jokinen, 2005).

Hatzidimitriadou & Milne (2005) argue that in the UK current service delivery is characterised by fragmentation, limited resources and specialist care and inadequate training for staff. Problems identified in other studies include; widespread confusion about which agencies and professionals were responsible for providing services for this client group (Fitzgerald, 1998); lack of investment in specialist services for this client group, limited access to psychiatric and general health care services and low expectations of users by staff (Aspray, Francis, Tryer & Quilliam, 1999; Dagnan & Ruddick, 1997; Duff, Houghton, Scheepers, 2000; Hassiotis, Barron & O’Hora, 2000).
These difficulties in providing co-ordinated and responsive services result in care decisions based on available resources rather than a coherent strategy and are often dictated by a crisis, resulting in rapid decline and in some cases premature death (Wilkinson, Kerr, Cunningham & Rae, 2004; Thompson and Wright, 2001). These studies largely concentrate on the structural dimensions of care but seem to neglect the psychosocial aspects of dementia care. This is not surprising as evaluating ID dementia care is still embryonic. Measuring psychosocial dimensions of care has been extensively researched in the older adult literature and Dementia Care Mapping (DCM) is an example, designed to promote an understanding of dementia care from the viewpoint of the person with dementia (Kitwood, 1997). DCM is grounded within person-centered approaches to dementia care and records both the quality and quantity of staff behaviors over a care day as well as assessing the well being of the client through systematic observation and recording. These findings are then shared with the staff to raise awareness of care practices and their effects on people in their care. DCM has proved to be a valid measure for frontline staff as well as those commissioning care, providing detailed information on quality of life in dementia care (Brooker, 2005). DCM offers a starting point in considering the psychosocial dimensions of care for this client group but to date seems to have had little impact on ID services.

*Service provision for older adults*

As there is a paucity of literature on service provision and delivery in the ID field it is useful to draw on research and practice from the older adult literature. Service provision for people with suspected and diagnosed dementia in the general population is primarily delivered through primary care and specialist services such as memory clinics which are
situated within old age psychiatry services (Department of Health, 2001b). The ethos of such clinics is to provide early diagnosis as well as advice on how to manage the condition (Foreman, Gardner & Davies, 2004). Passmore & Craig (2004) identified the benefits of early diagnosis as providing access to treatments, planning of future care, helping the family to come to terms with prognosis and to help understand changes in memory, behaviour and personality. Memory clinics are typically multi-disciplinary and usually a patient will see representatives from psychology, psychiatry and sometimes nursing and social work in a single appointment.

Attempts have been made to bring the memory clinic model to the ID population namely in Canada (McCreary, Fotheringham, Holden, Ouellette-Kuntz & Robertson, 1993), the USA (Chicoine, McGuire & Rubin, 1999) and the UK (Hassiotis, Strydom Allen & Walker, 2003). The UK authors concluded that the framework of a memory clinic was useful but without additional funding difficult to implement long term.

Clinical Issues in Older Adult Services

An issue that has been debated extensively in the older adult literature is how clinicians disclose a diagnosis of dementia. The NSF for older people (Department of Health, 2001) has specifically identified the importance of early diagnosis of dementia in enabling people and their families to respond effectively and that this should always involve explaining the diagnosis to the older person and any carers.

With the development of new drug regimes that can slow down the progression of the early stages of dementia, the disclosure of diagnosis has gained prominence as clinicians
are required to seek consent before commencing drug treatment. The responsibility of disclosure can fall to GPs or specialists in secondary and tertiary services. Research on disclosing a diagnosis of dementia has found both perceived positive and negative consequences. For example, research into GPs attitudes towards disclosure identified the following reasons for not disclosing: wariness of misdiagnosis (Cody, Beck, Pope & Shue, 2002; Milne, Woolford, Mason, & Hatzidimitriadou, 2000); inability to offer effective treatments (Milne et al., 2000; Van Gool & Van Crevel, 1996); time constraints (Milne et al., 2000; Olafsdottir, Skoog & Marcusson, 2000) and stigma (Vernooij-Dassen et al., 2005).

Psychiatrists, geriatricians and mental health clinicians have postulated similar reasons and also have concerns such as patients’ poor cognitive insight (Johnson, Bouman, & Pinner 2000; Rice, Warner, Tye & Bayer, 1997), the risk of causing distress as a result of receiving the diagnosis which may in turn bring an onset or exacerbation of depression, induce feelings of hopelessness and a catastrophic reaction (Claffery, 1999; Johnson, Bouman & Pinner, 2000; Keightley & Mitchell, 2004) or even suicide (Rhode, Peskind and Raskind, 1995). However, the combination of advances in medication with psychosocial interventions, availability of clear and accurate diagnostic criteria in ICD 10 and DSM IV and a paucity of evidence to support a risk of depression indicates that clinicians’ reasons for disclosing may well be unfounded. Evidence suggests that the benefits of disclosure are numerous, both practical and moral. Pinner (2000) argues that disclosure facilitates future planning and it may assist in persuading the patient to accept help and in managing social needs. Legal matters such as ‘power of attorney’ and ‘living wills’ can be addressed, understanding the potential consequences of the disease can be
facilitated such as the limitations of one’s capacity to drive safely (Johnson & Bouman, 1997). Finally disclosure addresses carers’ and patients’ professed wishes to know (Marzanski, 2000; Wilkinson & Milne, 2003).

In understanding the subjective experience of people with dementia a number of models have attempted to describe, explain and conceptualise the experience of people with dementia (Keady & Nolan, 1995; Harris & Stein, 1999; Clare, 2002). Pratt and Wilkinson (2003) propose a model which takes account of both individual responses and the social context to understand the experience of people with dementia (see figure 1). The model proposes that individual experience can be located in any of these ‘quadrants’ as a function of the combined effect of social context and individual response.

Figure 1

A psychosocial model of understanding the experience of receiving a diagnosis of dementia (Pratt & Wilkinson, 2003)

Ability and desire to know diagnosis (high)

Distress

Maximising coping strategies

Social context (negative) → Social context (positive)

Attachment

Decline and denial

Ability and desire to know diagnosis (low)
Method

This study utilized a dual methodology, namely a quantitative and qualitative approach. A quantitative approach lends itself to gathering large scale data and a questionnaire was decided upon as this could be distributed to clinical psychologists across the UK. The researcher anticipated there would be issues arising from the questionnaire data that would warrant further discussion, such as moral and ethical considerations arising from discussing dementia, lending themselves much more to an in depth qualitative methodology. A focus group methodology was employed to explore the views, beliefs and ideas of clinical psychologists more fully.

Questionnaire design

A questionnaire was designed reflecting a possible dementia assessment pathway including receipt of referral, pre-assessment meeting, dementia assessment, post-assessment and feedback meeting and intervention. An additional section was added to elicit participants’ agreement with a series of statements postulating possible risks and benefits of disclosing a diagnosis of dementia. Each section requested answers to both closed and open-ended questions. The closed questions invited a numerical response, a yes/no response or a 5 point Likert scale with responses ranging from never to always (Appendix 1). Open questions invited participants’ comments to questions such as ‘how is the purpose of the assessment explained to the carer prior to the assessment?’. The questionnaire was distributed to peers and professionals to check face validity and invite comments on the ease of reading and completing the questionnaire. This process prompted several drafts before a final version was submitted for ethical approval.
Questionnaire participants

Clinical psychologists specialising in ID were recruited from across the UK. Two recruitment routes were employed. Firstly, participants were invited to complete the questionnaire during their attendance at a national 3-day conference held annually by the BPS Faculty of Learning Disabilities. Of the 95 people attending, 17 returned questionnaires. An e-mail reminder was sent to the attendees, generating a further 8 completed questionnaires. The second recruitment route was through the Faculty of Learning Disabilities Newsletter which is distributed quarterly to all 250 faculty members. A further 37 were returned, generating 64 completed questionnaires in total, an 18% response rate.

Ethics

Ethical approval was sought and gained from the Multi-Centre Research Ethics Committee for Scotland (see Appendix 2).

Analysis of questionnaire data

As the questionnaire generated two discrete forms of data, namely responses to open and closed questions, two methods of analysis were utilized. For closed question data descriptive statistics were derived using SPSS. Open question responses were analysed using Content Analysis which entails establishing categories and then counting the number of instances in which they are used in a text (Joffe & Yardley, 2004). Four responses or more were deemed sufficient to warrant a coding. These categories provided a platform from which the researcher formulated questions for further discussion in the focus groups.
Focus groups

A focus group is a way of collecting qualitative data and essentially involves engaging a small number of people in an informal group discussion ‘focused’ on a particular topic or set of issues (Millward, 1995; Kitzinger, 1995). The discussion is commonly based around a series of questions and the researcher acts as a facilitator for the group, posing the questions, keeping the discussion flowing, and encouraging people to participate fully. The overall aim of a focus group is for participants to interact and communicate with each other eliciting rich data. It is a flexible method that can either be used as a stand alone qualitative method or in conjunction with quantitative research.

Interview Schedule

The questions were informed by findings from the questionnaire data and key issues from the ID and older adult literature. The schedule consisted of five questions designed to engage the participants and allow a variety of viewpoints to be expressed (see Appendix 3)

Focus group participants

An information letter attached to the questionnaire invited participants to consider attending a focus group to discuss the issues arising from the questionnaire in more depth. From those who volunteered, the researcher looked for geographical clusters of respondents and chose the most convenient location for the majority of participants to attend. Two groups were held, one in the North Thames Region (n=6), London and one in the South Thames region (n=5), Surrey. Both groups took place on the regional Special Interest Groups days to encourage attendance and minimise inconvenience for
participants. The majority of participants had been working in intellectual disabilities for a significant period of time (mean 9.2 years, S.D 6.7) and were employed in ID services within North London or Southeast England, both in urban and more rural services.

Focus group procedure
On arrival participants were asked to read and sign the consent form (see Appendix 4). The researcher gave a brief overview of the study and the purpose of conducting the focus group and obtained consent for tape recording the discussion.

Focus Group Analysis
As the research questions elicited both experiential data and factual data the data was analysed according to the principles of Thematic Analysis (Joffe & Yardley, 2004, Luborsky, 1994). The purpose of thematic analysis is to represent directly an individual's own point of view through descriptions of experiences, beliefs and perceptions (Park, Butcher & Maas, 2004) and has been extensively used in clinical and health psychology studies e.g. Butcher, Holkup, Park & Maas (2001); Loewenthal, Lee, MacLeod, Cook & Goldblatt, (2003).

When identifying themes the researcher needs to hold in mind whether the theme is drawn from existing theoretical ideas that the researcher brings to the data, known as deductive coding or from raw information itself, known as inductive coding (Joffe & Yardley, 2004). It is recommended that themes flow from the principles that underpin the research and the specific questions one seeks to answer. In this study the themes are informed by the older adult and ID literature.
Joffe and Yardley (2004) recommend the researcher moves through a series of stages when analysing the data; initial readings of the transcripts; followed by identifying very specific initial themes (see Appendix 5); followed by identification of fewer more powerful categories allowing for higher order abstraction and interpretation. The final stage is to present a table of overarching themes that encapsulate these categories (see results section, table 15).

Credibility Checks
In order to ensure that qualitative analysis represents the data, Elliott, Fischer and Rennie (1999) recommend conducting credibility checks. In this study I provided all participants with a summary of major themes derived from the initial analysis of the transcripts and participants were invited to comment. My supervisor also examined the transcripts and during supervision we discussed evolving themes and agreed upon the final table of themes.

The researcher's perspective
Good practice guidelines in qualitative research recommend that the researcher explicitly acknowledges his or her own theoretical orientation and expectations relevant to the area under investigation (Elliott, Fischer & Rennie, 1999). Prior to commencing clinical training, I worked for various organisations both public and voluntary, offering support to PWID and was struck by the usefulness of acknowledging the wider system and its impact. These thoughts were later formalized by clinical teaching in systemic working whereby I was able to understand the importance of our own beliefs, values and
ideals in clinical practice. In conducting this study I expected to find issues spanning the wider system from national to local level, highlighting political, economic and societal concerns as well as participants' thoughts on PWID's ageing as well as their own.
Results

Questionnaire Data

The questionnaire aimed to capture how clinical psychologists proceed when assessing a client with Down’s syndrome and ID for signs of dementia. Each section of the questionnaire will be discussed in turn and unless otherwise indicated each table indicates respondents’ responses to a 5 point Likert scale.

Receipt of referral phase

78% (n=64) of respondents were able to provide information about the number of referrals for dementia. Their responses ranged from 0-39 referrals (mean 6.2, SD 6.8). The majority of referrals were derived from within the Community Learning Disability Team. The time lag between receipt of referral to an initial appointment with a clinical psychologist varied from 0 to 52 weeks (minimum time 0-24 weeks, mean 3.2 weeks, SD 3.6 and maximum time 0-52 weeks, mean 13.4, SD 11.6). Services conducting prospective baseline assessments and follow ups indicated 0 referrals and 0 waiting times as they proactively identify people with Down’s syndrome at risk of developing dementia and invite them for an assessment.

Pre-Assessment Phase

Questions in the pre-assessment section focused on what happened at the first appointment. Respondents stated that paid carers were nearly always given an explanation of the purpose of the assessment (mean 4.4, S.D .71) whereas clients were less likely to be informed (mean 3.8, S.D 1.1).
There were qualitative differences between what was typically said to clients and carers (see Tables 1 and 2). Carers received explicit information about the risk of people with Down’s syndrome developing dementia whereas clients typically received an explanation of the assessment process with regards to their strengths and deficits, with no reference to dementia. Only 6 respondents reporting that they would talk about dementia with the client. Respondents stated that their preamble was dependent on clients’ cognitive abilities.

**Table 1**

*Key points of respondents’ discussions with carers prior to an assessment*

<table>
<thead>
<tr>
<th>Carer</th>
<th>No. of Respondents*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increased risk of dementia and Down syndrome explained</td>
<td>30</td>
</tr>
<tr>
<td>“find out what the carer knows and explain the link between Down Syndrome and Alzheimer’s.”</td>
<td></td>
</tr>
<tr>
<td>Need to reassess explained</td>
<td>20</td>
</tr>
<tr>
<td>“explain that it will be repeated in the future to help pick up early signs.”</td>
<td></td>
</tr>
<tr>
<td>Same explanation as to client</td>
<td>18</td>
</tr>
<tr>
<td>To identify what support needs can be offered</td>
<td>16</td>
</tr>
<tr>
<td>Explain the process of assessing</td>
<td>16</td>
</tr>
<tr>
<td>Differential diagnosis/stress clear diagnosis unlikely</td>
<td>10</td>
</tr>
<tr>
<td>Discuss possible reasons for a change in clients’ presentation</td>
<td>7</td>
</tr>
</tbody>
</table>

* Number of respondents who indicated this point in their discussions
### Table 2

**Key points of respondents’ discussions with clients prior to an assessment**

<table>
<thead>
<tr>
<th>Client</th>
<th>No. of respondents*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Explain what happens when assessing</td>
<td>28</td>
</tr>
<tr>
<td>“<em>we will do some puzzles with you and ask some questions of those who support you.</em>”</td>
<td></td>
</tr>
<tr>
<td>Look at strengths and deficits</td>
<td>19</td>
</tr>
<tr>
<td>“<em>I explain that we want to find out all the things they are good at and the things they find difficult.</em>”</td>
<td></td>
</tr>
<tr>
<td>Get consent to ask carers some questions</td>
<td>11</td>
</tr>
<tr>
<td>Depends on circumstances of referral and client’s abilities</td>
<td>16</td>
</tr>
<tr>
<td>Need to test now and in the future</td>
<td>9</td>
</tr>
<tr>
<td>Memory difficulties / getting older</td>
<td>8</td>
</tr>
<tr>
<td>“<em>sometimes people get problems with their memory as they get older.</em>”</td>
<td></td>
</tr>
<tr>
<td>To see what help can be offered</td>
<td>8</td>
</tr>
<tr>
<td>Talk about dementia</td>
<td>6</td>
</tr>
<tr>
<td>“<em>some more able individuals are aware of the issue of dementia and a fuller discussion can take place.</em>”</td>
<td></td>
</tr>
</tbody>
</table>

* Number of respondents who indicated this point in their discussions

93.8% of respondents said they used the term dementia at least sometimes when explaining the purpose of the assessment but there was variation as to who clinicians used the term with (Paid carer, 4.3, S.D .80, Family member, 3.8, S.D .79, Client, 2.2, S.D .84)

Participants reported that instead of the term dementia being used when explaining the purpose of the assessment, they would use a range of terms with both clients and carers, “*not being able to do things as well as before*” (n=13), “*problems remembering*” (n=10) and “*getting older*” (n=6). When asked why they might not use the term
dementia with clients and carers the following reasons were given: "many people don’t understand the term." (n=13), may cause upset/alarm before diagnosis known (n=10) and diagnosis not clear (n=4). This apparent caution about using the term dementia was discussed further in the focus groups where similar thoughts were expressed.

Assessment Phase

The next section of the questionnaire examined what methods and tools psychologists use when assessing a client for suspected dementia or performing a baseline assessment. A general health screen and a check of thyroid functioning were more likely to be requested and conducted by respondents than a MRI scan, (see Table a, Appendix 6). With regards to assessment tools, these ranged from longitudinal informant based assessments monitoring change across domains of functioning to psychometric and neuropsychological tools measuring cognitive functioning. As can be seen from Table 3 there is wide variation in the tools utilized by clinicians with the most frequently used tool being the DMR (mean 3.7, S.D. 1.71).
Table 5
Assessment tools most commonly used to assess for dementia

<table>
<thead>
<tr>
<th>Assessment Tool</th>
<th>Mean</th>
<th>S.D</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia Questionnaire for Persons with Mental Retardation (DMR)</td>
<td>3.7</td>
<td>1.71</td>
</tr>
<tr>
<td>British Picture Vocabulary Scales (BPVS)</td>
<td>2.8</td>
<td>1.4</td>
</tr>
<tr>
<td>Oliver &amp; Crayton Battery</td>
<td>2.7</td>
<td>1.7</td>
</tr>
<tr>
<td>Wechsler Adult Intelligence Scales (WAIS)</td>
<td>2.6</td>
<td>1.2</td>
</tr>
<tr>
<td>Rivermead Behavioural Memory Test (RBMT)</td>
<td>2.3</td>
<td>1.1</td>
</tr>
<tr>
<td>Down Syndrome Dementia Scale (DSDS)</td>
<td>2.2</td>
<td>1.6</td>
</tr>
<tr>
<td>Schonell Reading Test</td>
<td>1.5</td>
<td>.90</td>
</tr>
<tr>
<td>Bournewood Battery</td>
<td>1.3</td>
<td>.85</td>
</tr>
</tbody>
</table>

Tools designed to assess emotional, behavioural and psychological functioning were used relatively rarely (see Table 6).
Table 6
Use of tools for the assessment of emotional/behavioural and psychological

<table>
<thead>
<tr>
<th>Tool</th>
<th>Mean</th>
<th>S.D</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adaptive Behavioural Scales (ABS)</td>
<td>2.9</td>
<td>1.7</td>
</tr>
<tr>
<td>PASS-AD</td>
<td>2.6</td>
<td>1.5</td>
</tr>
<tr>
<td>Vineland Adaptive Behaviour Scales</td>
<td>2.3</td>
<td>1.4</td>
</tr>
<tr>
<td>Adaptive Behaviour Assessment System (ABAS)</td>
<td>2.0</td>
<td>1.3</td>
</tr>
<tr>
<td>HALO</td>
<td>1.5</td>
<td>1.7</td>
</tr>
<tr>
<td>Holmes-Rahe Life Event Checklist</td>
<td>1.5</td>
<td>1.2</td>
</tr>
<tr>
<td>Reiss Screen for Maladaptive Behaviour</td>
<td>1.3</td>
<td>.99</td>
</tr>
</tbody>
</table>

78% of respondents stated they routinely took a history from the carer in addition to completing formal assessment tools. Areas of daily functioning such as mobility, sleeping, eating, drinking and nutrition were routinely discussed with carers. Depth perception was sometimes discussed (see Table b, Appendix 6) but some respondents queried the inclusion of depth perception on the questionnaire and stated they were unsure how to assess this area.

Overall clinicians cited various reasons for not using certain assessment tools, for example, not being familiar with the tools listed in the questionnaire or that the tools
were not part of the protocol used in their service (n=9). A few respondents commented that some of these tests were done elsewhere or by someone else (n=5) or that the tools were not available (n=6). This variation was discussed in more depth in the focus groups.

**Feedback Phase**

Invariably participants said they gave feedback of assessment results to the referrer in a written report, 44% supplemented this with face to face feedback (n=64). 31% of respondents gave both face to face and written feedback to the client (n=64), with the majority of these respondents stating that they modified the written report in line with the client’s level of understanding. 20% (n=64) of respondents stated that feedback was not given to the client. GPs are frequently informed of the results of the assessment but by no means always (mean 4.5, S.D .80), and the client’s family only sometimes (mean 3.7, S.D .89).

In cases where the assessment results point to a probable diagnosis of dementia, respondents were asked who they disclosed this to. As Table 7 shows clients are least likely to be given a diagnosis of dementia.
Table 7
Who is a diagnosis of dementia disclosed to?

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>S.D</th>
</tr>
</thead>
<tbody>
<tr>
<td>CLDT</td>
<td>4.8</td>
<td>.44</td>
</tr>
<tr>
<td>GP</td>
<td>4.7</td>
<td>.60</td>
</tr>
<tr>
<td>Paid carer</td>
<td>4.6</td>
<td>.82</td>
</tr>
<tr>
<td>Client family</td>
<td>4.1</td>
<td>.91</td>
</tr>
<tr>
<td>Client</td>
<td>3.2</td>
<td>1.1</td>
</tr>
</tbody>
</table>

**Intervention Phase**

Respondents were asked what interventions their services commonly offer following a diagnosis of dementia. 70.3% said that their service routinely considered medication to slow deterioration or target specific symptoms. In practice medication was only sometimes given, with Donepezil the most commonly prescribed, (29.7%, n=19), followed by Rivastigmine (10.9%, n=7) and Galatamine (7.8%, n=5). Participants stated that psychiatrists were not keen to prescribe due to a paucity of evidence for drugs’ effectiveness (n=9).

With regards to non-pharmaceutical interventions, staff training for paid carers was most frequently offered (3.8, S.D 1.1) followed by psycho-education programmes for carers (3.6, S.D .94) and family members (3.3, S.D .90). Therapy and psycho-education programmes were less frequently offered to clients (2.8, S.D .94). Therapies such as reality orientation, cognitive stimulation and support groups, widely offered to older adults without learning disabilities and their carers, were utilised less by respondents (see Table c, Appendix 6).
Risks and benefits of disclosure

Respondents were asked to rate their agreement with statements regarding the benefits and risks of disclosing a dementia diagnosis to a client, using a 5 point Likert scale ranging from 1 = strongly disagree to 5 = strongly agree, see Table 9.

Table 9
Agreements with statements regarding potential benefits of disclosing a diagnosis of dementia

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>S.D</th>
</tr>
</thead>
<tbody>
<tr>
<td>Facilitates future planning</td>
<td>4.8</td>
<td>.52</td>
</tr>
<tr>
<td>Right to know</td>
<td>4.6</td>
<td>.68</td>
</tr>
<tr>
<td>Allows client and family to make the most of opportunities</td>
<td>4.4</td>
<td>.71</td>
</tr>
<tr>
<td>Maximises treatment options</td>
<td>4.4</td>
<td>.74</td>
</tr>
<tr>
<td>Brings psychological benefits</td>
<td>4.0</td>
<td>.79</td>
</tr>
<tr>
<td>Makes it easier to obtain a second opinion</td>
<td>3.9</td>
<td>1.0</td>
</tr>
</tbody>
</table>

Table 10 shows respondents’ levels of agreement with statements citing possible risks of disclosing a diagnosis of dementia. Respondents generally agreed that a client’s capacity to understand and the possibility of undue distress were risks to consider when disclosing a diagnosis. This data was explored in more depth in the focus group discussion (see section 2.1).
Table 10

*Agreement with statements regarding the potential risks of disclosing a diagnosis of dementia*

<table>
<thead>
<tr>
<th>Statement</th>
<th>Mean</th>
<th>S.D</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clients unlikely to understand/retain diagnosis</td>
<td>3.6</td>
<td>1.0</td>
</tr>
<tr>
<td>May cause undue emotional distress</td>
<td>3.4</td>
<td>1.0</td>
</tr>
<tr>
<td>Significant stigma attached to ‘dementia’</td>
<td>3.2</td>
<td>1.0</td>
</tr>
<tr>
<td>Evokes personal fears of death and ageing</td>
<td>2.8</td>
<td>1.3</td>
</tr>
<tr>
<td>Unhelpful as often one cannot be confident about diagnosis</td>
<td>2.4</td>
<td>1.0</td>
</tr>
<tr>
<td>Fear of being blamed if diagnosis is inaccurate</td>
<td>2.3</td>
<td>1.0</td>
</tr>
<tr>
<td>Costs of disclosure outweigh benefits</td>
<td>2.3</td>
<td>.81</td>
</tr>
<tr>
<td>Service culture not to routinely tell people</td>
<td>2.2</td>
<td>1.3</td>
</tr>
<tr>
<td>Unhelpful due to lack of treatment options</td>
<td>1.9</td>
<td>.98</td>
</tr>
</tbody>
</table>
Focus groups

In the focus groups participants were asked to reflect on possible reasons for the variation in assessment practices evident in the questionnaire data, similarities and differences in practice between clinicians working with ageing PWID and those working with older adults in the general population. They were also asked to consider what they would like to change, in their practice and their service, to meet the needs of this ageing cohort better. Finally participants were asked to reflect on their experiences of discussing dementia with clients with ID.

The thematic analysis yielded several themes, summarised in Table 11. Participants described a range of experiences, explanations and beliefs about working with ageing clients with ID. Several dilemmas were repeatedly apparent in the participants' narratives, with most accounts marked with uncertainty, frustration and a wish for change.

Each research question will be considered in turn with reference to the overarching themes which emerged from the thematic analysis. Each theme is defined and illustrated with direct quotations from participants (the source of each quotation is indicated by the participant number). Where quotes have been edited for brevity, missing words are denoted by '......'.
Table 11
*Overarching Themes*

<table>
<thead>
<tr>
<th>Focus group questions</th>
<th>Overarching themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. What issues arise from assessing dementia in PWID?</td>
<td>1.1 Problems with assessment</td>
</tr>
<tr>
<td></td>
<td>2.1 Physical and psychological needs</td>
</tr>
<tr>
<td>2. What similarities and differences do you see between ID services and older adult services?</td>
<td>2.2 Contextual &amp; societal issues</td>
</tr>
<tr>
<td></td>
<td>2.3 Different work practices</td>
</tr>
<tr>
<td></td>
<td>2.4 Organisational differences</td>
</tr>
<tr>
<td></td>
<td>2.5 Specialist versus generic</td>
</tr>
<tr>
<td>3. What is currently not working?</td>
<td>3.1 Shortcomings in service provision</td>
</tr>
<tr>
<td></td>
<td>3.2 Need for strategic planning</td>
</tr>
<tr>
<td></td>
<td>3.3 Solutions</td>
</tr>
<tr>
<td>4. What are your experiences of discussing dementia with PWID?</td>
<td>4.1 Difficult to talk about and be open</td>
</tr>
<tr>
<td></td>
<td>4.2 Uncertainty in diagnosis</td>
</tr>
<tr>
<td></td>
<td>4.3 Is it our role?</td>
</tr>
<tr>
<td></td>
<td>4.4 What would I do if it was me?</td>
</tr>
</tbody>
</table>
1. What issues arise when proceeding from assessing dementia in PWID?

1.1 Problems with assessment

This theme reflects the various problems participants reported when assessing clients for dementia, namely the wide variation in assessment tools, lack of standardised tools, inconsistent informants and the need for normative data.

"It would be lovely if we did have a pack that was very suitable, very appropriate for people with learning disabilities. We keep saying we need to get one together, or kind of waiting and hoping that someone else is gonna do it." (P2)

"For me it is less about the assessment and more about the people, the informant. We have just done one recently and of course the informant, you know, isn't as knowledgeable as previous informants." (P1)

2. What similarities and differences do you see between ID services and older adult services?

The following themes represent the numerous differences, both for clients and clinicians which participants felt existed between their service and a typical older adult service.

2.1 Physical and psychological needs

Participants spoke of different physical needs a person with ID has, such as increased health needs and an increased dependency on family and carers as dementia progresses. Participants commented on the psychological processes that may be impaired, for example, participants felt that people with ID are less likely to reflect and monitor change in themselves.

"People with learning disabilities' health needs are appalling, much more in terms of the kind of services they receive or many conditions go unrecognised for much longer for all sorts of reasons." (P5)
"I think that our clients are doubly disadvantaged because you know it is a difficult thing to think about and maybe they don't have the capacity to reflect on their own life in the same way, recognise when they change and they may not have consistent caregivers who know much about them." (P2)

2.2 Contextual and Societal issues

Participants discussed a number of contextual issues that differ from older adults services, for example a lack of appropriate resources such as accommodation and day centres for ageing PWID. Participants also felt that society was less likely to acknowledge and mark life transitions for PWID such as growing older and retirement.

"I think there is a history how people with learning disabilities were treated, there is infantilisation, almost a block on thinking that our client group will grow older...that people aren't seen to grow up and to have more stages of life." (P1)

2.3 Different work practices

Participants felt that their work differed to clinicians working with older adults in the general population, namely that working with ageing PWID is only a small part of their daily clinical practice and that they lack specialist knowledge.

"in learning disabilities you find yourself being the jack of all trades and sometimes the master of none." (P10)

2.4 Organisational differences

Participants perceived there to be organisational differences between older adult and ID services. ID services are, for example, not designed to meet the needs of an ageing cohort. Participants reported fragmented and inappropriate services for this cohort as well as an absence of a cohesive strategy for assessment and intervention.

"Residential homes and day services, their background is in learning disabilities so think about how they are having to adapt to the needs of older clients and service users." (P4)
"I think we have to negotiate so much more and cobble together things, you know rather than having a proper process, proper assessment, proper places to place people." (P7) (discussing older adult services)

2.5 Specialist versus Generic ID Services

Despite the concerns about lack of specialist services for ageing adults with ID, participants expressed a reluctance about setting up services targeting ageing or older adults with ID. Participants felt that it would be more advantageous for clients to stay with a generic ID service, emphasising the lifespan approach many clinicians adopt. Participants felt that the specialist skills needed to address the changing needs resulting from dementia, in some cases, were already present within generic ID teams or could be developed.

"I think the danger is that the client loses the relationship with their community nurse or care manager when they are moved to a different team just because they have got to a certain age and I think our clients have enough loss or too much loss and change already." (P11)

"you take the problems that exist, for example a change of behaviour in dementia, is not only a problem that someone in dementia could look at. Also people working with challenging behaviour skills who can offer a great deal of advice around that." (P8)

3. What is currently not working?

3.1 Shortcomings in service provision

Participants noted that a lack of appropriate resources and options once a client has been diagnosed with dementia. Participants described a lack of suitable accommodation for individuals with dementia and high support needs which at times resulted in them being moved out of borough, resulting in further disruption, loss and confusion.
there is a lack of awareness and for a lot of people their needs are going to be increased and so you get a crisis reaction, knee jerk, we haven’t got any money ..what are we going do?” (P8)

3.2 A need for strategic thinking and planning

Participants spoke about a need for more strategic planning to take place both in terms of designing a national dementia care pathway as well as local planning for accommodation and day care services.

‘rather than all of us in our areas making our own pathways up, there ought to be an agreed best practice.’ (P9)

3.2 Solutions

In considering what would improve the daily practice of psychologists and services, participants offered a range of ideas from improving dialogue between and within teams, improving the reliability and validity of assessment tools, particularly in developing normative data, to increasing our understanding of risk assessment as the client’s dementia progresses. There was a consensus that there needs to be an increase in funding and resources.

‘I think the splits in the system are the worst..when there are fundamental differences in dementia.. between agencies so you have a health team view, a community team view here and social services view and the independent provider view. If they are all at loggerheads it’s then very difficult for all the client’s needs to be met and certain specific needs go a miss.’ (P8)
4. What are your experiences of discussing dementia with PWID?

Participants were asked to reflect on their experiences of discussing dementia with clients either in the pre-assessment or feedback phase of a dementia assessment. The themes that arose indicate both professional and personal dilemmas.

4.1 Difficult to talk about and be open

All of the participants spoke of how they struggled to broach the subject of dementia with a client and felt very unsure whether the client wanted to know or not. Arising from this discomfort was a desire to avoid using the term ‘dementia’, with participants stating that they would usually discuss changes the client was experiencing by using modified explanations or pseudonyms. Participants gave a variety of reasons for their reluctance to use the term dementia including a wish to protect clients from undue emotional distress and that clients may not have the capacity to understand what is being discussed with them. It was evident from the discussions that participants clearly grappled with these dilemmas and were keen to reflected on the ethics of their clinical practice.

"'This is something I have been grappling with a lot, should I be saying to someone this is why we are doing it or not.'" (P7)

'I do wonder whether there is a degree of subterfuge if the term dementia isn't actually used with people who are being approached to do this.'" (P3)²

'I don't always honestly talk about the reasons that I am there.'" (P7)
Participants also discussed how their conversations with clients differed from those with carers and other professionals and it was often difficult to be open about the rationale and purpose of the assessment.

'I am different with, perhaps with doing my first initial assessment with someone at a day centre than with a family, tend to be much more open with carers or day centre staff than with families.' (P10)

4.2 Uncertainty in diagnosis

The frequent lack of certainty regarding the diagnosis and prognosis of dementia in this client group was extensively discussed by all participants. Not only did this uncertainty lead participants to refrain from discussing dementia with a client but they also expressed a sense of frustration that their clinical practice was impeded by a paucity of research and a lack of valid and reliable tools.

'I think one of the additional dilemmas is that tools we use aren't particularly reliable and so in my experience when I am sure it is dementia, everyone else is sure as well because someone has had to deteriorate so much.' (P7)

4.3 Is it our role?

Participants described being unsure whose role it is to diagnose and therefore disclose a possible diagnosis. Participants questioned whether this was the professional domain of psychiatry or clinical psychology.

'I suppose I feel that we are not diagnosticians here anyway, we are clinical psychologists and yes for me if we do find some deterioration, then that’s what it is deterioration. We would then talk to GPs and psychiatrists to investigate further, to diagnose whether someone is dementing.' (P1)
4.4 What would I do if it was me?

Participants drew on their personal experience as well as related examples to inform their decision making about whether or how to discuss and disclose a diagnosis of dementia.

"But if any of us went for a screening I'd presume we'd want to ask why; why us, why have we been chosen." (P3)
Discussion

Participants in this study reported numerous difficulties when assessing a client with ID for signs of dementia. They also reported perceiving differences in their practice to clinicians working with older adults. These differences appeared to reflect the range of additional difficulties that manifest from a client’s premorbid intellectual disabilities as well as feeling that, compared to older adult clinicians, their caseloads differed as they do not work exclusively with ageing adults. All participants expressed their frustration with the paucity of resources and service provision for this cohort. All participants reported concerns and dilemmas when discussing dementia with a client with ID.

Clinical Issues

Participants highlighted the wide variation in tools utilised to assess for dementia in PWID. With more than 80 assessment tools identified in the literature (Sano et al., 2005) it is hardly surprising that clinicians are unsure of which tools to use. The International Association for the Scientific Study of Intellectual Disability (IASSID) have recommended tools to assess the cognitive, behavioural and emotional domains of functioning in PWID presenting with signs of dementia (Aylward, Burt, Thorpe, Lai & Dalton, 1997). From the questionnaire data it would seem that many participants rarely use standardised tools to assess for emotional and behavioural changes despite this being a key domain to assess. Some participants commented on the availability of these recommended tools and other participants reported that they cover these areas in a clinical interview. Yet Deb & Braganza (1999) concluded that standardised tools were more useful due to increased sensitivity and specificity when compared to a clinician’s diagnosis. With emerging frontal lobe theories stressing that early behavioural changes
in people with Down’s syndrome and early DAT are the consequence of premature and unrecognised cognitive decline in functions served by the frontal lobes e.g. executive functioning (Holland, Hon, Huppert, Stevens & Watson, 2000; Rowe, Lavender & Turk, 2006), it is worrying that questionnaire participants in this study rarely seemed to assess emotional and behavioural areas. Diagnostic clues may be missed or mis-attributed to challenging behaviour, particularly in those with severe and profound ID.

Great frustration was expressed in the focus groups about the lack of standardised tools and many felt it impeded their abilities and confidence to carry out an accurate assessment. This is not surprising as many problems arise from the inherent variability in the degree of intellectual disabilities and the cognitive impairments associated with ID (Oliver, 1999). Participants reported using a range of neuropsychological, psychometric, observer and informant rated measures, yet each of these tools has its drawbacks in assessing dementia in people with ID, particularly when used retrospectively. Many of these tests have not been standardised on an aging ID population, consequently dementia may represent only one of several equally probable explanations for declines in cognitive functioning.

Several participants reported using retrospective assessments rather than the recommended prospective strategies by IASSID. Oliver (1999) argues that retrospective assessments may not include items sensitive to the early signs of dementia and if the clinician has used a psychometric tool that was not designed for the detection of cognitive impairments associated with dementia, then clearly the change noted may not be specific to dementia. Focus group participants also expressed their frustrations at
using informant measures and finding a 'good' informant. Informant measures used retrospectively are problematic with major difficulties regarding reliability and validity as the informant is relying on their memory. The informant may not have known the person long enough or received adequate training to recognise early signs of dementia in this client group.

Leading proponents of using prospective strategies argue that there are ethical consequences of deciding not to put the time and effort needed to conduct a proper prospective evaluation knowing that people with Down's syndrome are at a high risk of developing dementia (Oliver, 1999). It is unlikely that many clinicians would disagree with this statement, however in reality, constraints on time and resources as well as the ethical dilemmas that arise may prevent clinicians from conducting prospective evaluations. Many participants commented they felt uncomfortable discussing the potential risk of dementia when conducting a baseline assessment, yet were aware they were withholding information which the client may understand and want to know.

In view of lack of guidance on this issue participants spoke of drawing on their personal experience to guide their decision of what to discuss with the client by asking themselves what would be acceptable to them if they were asked to participate in a screening assessment. Using heuristic strategies to make a decision is common (Kee et al., 2002). Decision making research has developed models to understand professional decision making, for example in domains of medicine (Wigton, 1996) education (Heald, 1991) and law (Dhami, 2003). Dhami (2003) argues there are ideal and heuristic ways of making a decision and that in times of stress or time constraints people depart from the
ideal. An ideal decision is arrived at by gathering all the relevant information or cues available then weighting and combining the cues through a compensatory method, for example a low weight attached to one cue is compensated by a high weight attached to another cue, thus an informed decision is made. A heuristic decision, on the other hand, is arrived at by basing a decision on the value of one cue (Dhami, 2003). In this study it was evident that participants gave high weight to cues of their own experience but did not appear to compensate by attending to other low weight cues such as research findings. While this heuristic practice is line with the recommendation that all interventions with PWID should be acceptable to those without ID (Emerson et al., 1998), arguably it may result in highly variable practice and is less than ideal.

In addition to ethical dilemmas, some participants noted that identifying clients in their 30s and 40s may also be problematic. Indeed the Department of Health (2001a) estimates that up to a quarter of PWID are not known to services until their older family carers are unable to continue to provide support. Despite these potential drawbacks a prospective assessment currently offers the best approach to identifying and monitoring people with Down’s syndrome at risk of developing dementia.

Following assessment a clinician considers what interventions, if any, to offer the client and those caring for him/her. Participants reported considering dementia medication, such as cholinesterase inhibitors, but noted that psychiatrists were often reluctant to prescribe due to limited evidence base. With this in mind the use of psychosocial interventions takes precedence. Participants reported rarely offering interventions directly to clients following a diagnosis of dementia, instead they described using staff
training and psycho-education programmes with paid carers and family members. Interestingly, therapies such as reality orientation, cognitive stimulation and support groups were amongst the interventions rarely offered to clients, yet these are widely used with older adults to promote and strengthen existing cognitive abilities (Grasel, Wiltfang & Kornhuber, 2003).

Possible reasons for not offering these therapies could be due to the presence of pre-morbid cognitive deficits or because people with Down’s syndrome and dementia are often diagnosed later thus reducing the effectiveness of these interventions (Dodd, 2005). It may also reflect deterministic ideas that little can be done to ameliorate the dementia symptomology. It could also be speculated that a reductionistic paradigm, whereby dementia is viewed from a neuropathological stance, is more prevalent in the ageing and ID field neglecting the psychosocial dimension to dementia. This is certainly evident in the ageing ID literature where neuropathological studies are dominant (Jokien, 2005).

Tom Kitwood (1997) has vehemently argued that this deterministic view is wholly damaging to the person with dementia and in many cases accelerates the course of the disease. Neglecting the psychosocial and relational dimensions ignores the fact that they are intrinsically linked to the neuropathology. A dialectical model has been proposed by Kitwood (1997) to demonstrate how addressing the psychosocial dimension of dementia can impact on the neuropathology and in some cases stall the disease progression. A process known as rementing demonstrates powerfully the interaction between the these dimensions. People recover their capacities and skills that had been ‘lost’ once their
personhood and the psychosocial environment had been acknowledged and addressed. ID professionals may subscribe to the reductionistic paradigm unintentionally as they may not be aware, through lack of training, these psychosocial ideas prevalent in older adult service provision exist.

**Ethical issues**

The issue of discussing dementia, particularly in the context of disclosing a diagnosis, raises dilemmas for clinicians working with older adults (Bamford, Lamont, Eccles, Robinson, May & Bond, 2004). One of the aims of this study was to investigate whether ID clinical psychologists experienced similar dilemmas when discussing dementia with PWID. From both the questionnaire and focus group data there was a consensus that discussing dementia raises difficult thoughts and feelings. This finding is unsurprising as ‘breaking bad news’ can be stressful, particularly if one is inexperienced or in the early stages of their career (Ptacek, Ptacek & Ellison, 2001). All participants spoke of how they struggled to broach the subject, unsure whether the client wanted to know or not, yet many participants agreed in principle that the participant had a right to know. Although little is known about disclosure views of clients with ID, evidence from the older adult literature suggests that people want to know their diagnosis even if it will cause distress (Jha, Tabet & Orell, 2001).

Participants in this study recognised there was a discrepancy in the conversations they had with carers and professionals within the clients’ network and the conversations they had with the client when discussing dementia. Participants described themselves as far more open and honest in their discussions with carers and professionals than with
clients. This was found both in the pre-assessment and feedback phases and it was apparent from the data that a plethora of reasons underpinned this discrepancy, including the client’s ability to understand a concept like dementia, concern that discussions may cause undue distress to the client and that the diagnosis is often unclear. With clients, participants spoke of using euphemisms or normalising their symptoms as part of growing older instead of using the term dementia whereas with carers they were more likely to discuss the risks of dementia. Similar practice has been identified in older adult studies with clinicians reporting the use of modified or euphemistic explanations instead of the term ‘dementia’ with clients, while family members received a medicalised explanation including information on symptoms, cause, prognosis and where to access support. (Downs, Clibbens, Rae, Cook & Woods, 2002).

Keightley & Mitchell (2004) in their qualitative study with older adult clinicians concluded that this lack of certainty of whether to tell or not is fuelled by fear that to tell a person their diagnosis may cause harm. Participants in the present study expressed similar fears that undue emotional distress may result when discussing dementia, particularly in the initial stages of an assessment when it is unclear whether dementia is present or not. As well as causing distress, many participants in this study felt that having a dementia diagnosis could be significantly stigmatising, affecting access to resources and treatment.

Several participants in this study queried whether a PWID would have the capacity to understand the disclosure of dementia. They felt that many PWID present to services in advanced stages of dementia and their capacity to comprehend the disclosure would be
compounded by cognitive decline and premorbid low intellectual functioning. Researchers in the older adult field found that poor cognitive insight was advocated as a reason not to disclose by clinicians, reflecting a feeling of futility as the patient may no longer have the ability to understand or make use of the information (Johnson et al., 2000; Rice, Warner, Tye & Bayer, 1997). However, there is possible inconsistency between clinicians arguing that a disclosure may have a profound negative impact on the patients’ mental health yet also arguing that a patient may have poor insight and would be unable to retain and comprehend the explanation. One may wonder if a patient cannot comprehend and remember the disclosure how they are supposed to become depressed.

Participants in this study also felt that as professionals they were in a powerful position of withholding information that might well be imparted if the person did not have ID. Pinner (2000) argues ‘“the moral doctrine of diagnosis disclosure is derived from a respect for the patient’s autonomy as well as beneficence.”’ (p.514). The possible difference for PWID is that a priori they rarely have full autonomy over decisions about their health, accommodation and financial affairs and that decisions are often made for them. Therefore a philosophical shift in thinking is required if PWID are to be afforded more autonomy and be party to the same conversations had with carers and clinicians.

Participants felt that certainty regarding the diagnosis and prognosis of dementia was currently problematic and this uncertainty influenced their decision whether or not to tell a client their diagnosis. There is increasing consensus that longitudinal studies are more desirable (Holland et al., 2000; Carr, 2003; Zigman et al., 2004), however waiting for
the data from these studies takes time thus clinicians' confidence in the diagnosis is impeded.

Perhaps this lack of confidence and the discomfort manifesting from discussing dementia led some participants to query whether diagnosing and disclosing dementia is the responsibility of a clinical psychologist. Some participants noted that they tend to assess deterioration in clients' functioning and document this, leaving the final decision GPs or Psychiatrists. This position assumes that other clinicians feel confident in making a diagnosis of dementia in PWID. It may be hypothesised that similar reasons such as lack of research would also impede a psychiatrist or GP's diagnostic decision. Certainly in the older adult field psychiatrists and GPs report that they are wary of misdiagnosing, despite there being clear and accurate diagnostic criteria for DAT (Cody, Beck, Shue & Pope, 2002; ICD-10; World Health organisation, 1992; Pinner, 2000).

From this current study it was evident that guidelines to inform best practice when disclosing a diagnosis to PWID and dementia were urgently required. Participants reported wanting to act in client's best interests but feeling unable to do so due to the lack of research into PWID's experiences of receiving a diagnosis. While recognizing that no one set of recommendations will be optimal in all situations this paucity of research needs to be addressed urgently if models of best practice are to be developed and implemented. A starting point may be to look to other fields where these issues have been investigated, for example 'breaking bad news' literature is evident in cancer work (Girgis & Sanson-Fisher, 1995) and general medicine (Ptacek & Eberhardt, 1996). These studies offer guidelines on how doctors should prepare for delivering bad news,
how the environment should be structured while giving the bad news and how the news itself should be communicated (Fallowfield & Jenkins, 2004). Pratt & Wilkinson (2001) offer a psychosocial model to understand the experience of receiving a diagnosis of dementia. They argue that the clinician needs to take into account the social context as well as the individual psychological reaction when disclosing a diagnosis, including the attitudes and approaches of medical staff, access to information and the availability of formal and informal support. Negative social context combined with a wish to know will increase distress whereas positive social context and a wish to know will maximize positive coping strategies.

On a more positive note participants in this study strongly agreed that a disclosure facilitates future planning and allows the client and family to make the most of opportunities. Wilkinson and Milne (2003) argue that early diagnosis allows individual patients and their carers a number of decision making opportunities, in particular practical, legal and financial provisions for the future and may help introduction to appropriate services and support networks. It is less likely that clients with ID would have financial and legal affairs to put in order. However, decisions about accommodation and day care are paramount, therefore a diagnosis clarifies the client’s future needs and allows time for services to prepare.

Service provision

This study clearly demonstrates the gaps in service provision for ageing clients with ID. The focus group discussions revealed frustration at the lack of appropriate resources and facilities available for this cohort. These observations support Hatzidimitriadou and
Milne's (2005) finding that service delivery is fragmented and poorly organised. Participants felt there were a number of reasons contributing to this fragmentation at both national and local level, namely a lack of clear policy and lack of financial investment. Participants also felt that planning and commissioning of services for this cohort was patchy with decisions often made in crisis rather than in a planned way. Although Valuing People (Department of Health, 2001a) sets out a vision of partnership between generic older adult services, mental health services and ID services, guidance has not been forthcoming on how to operationalise these aims at the local level. This lack of clarity inevitable leads to fragmented and poorly delivered service provision.

From the focus group discussions it was apparent that clinical psychologists were taking the lead in developing pathways of assessment and intervention to meet the demand on their particular service. This has led to numerous pathways being developed but there was frustration, from the participants, that these pathways were not underpinned by a national strategy and, more importantly, funding. There was a clear message from the focus group discussions that similar national guidelines, such as the NSF for older adults, need to be developed and underpinned with investment.

Once a client has been diagnosed with dementia, care plans which take account of current and future health and care needs are required. Participants reported their frustrations at the paucity of options available, particularly with regards to accommodation and access to day activities. Similar findings have been reported in recent studies commissioning by The Growing Older with Learning Disabilities (GOLD) programme (Kalsy & Oliver, 2002; Thompson & Wright, 2001; Wertheimer, 2003; and
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the Joseph Rowntree Foundation (Wilkinson, Kerr, Cunningham & Rae, 2004). With regards to appropriate accommodation, Wilkinson, Kerr, Cunningham & Rae (2004) reported on the unsuitability of generic older adult residential homes for clients with ID. Participants, in this study, commented that often PWID were much younger than other older adults in generic residential settings plus staff are inexperienced in working with ID and dementia resulting in clients receiving a very poor service. Thompson and Wright's (2001) exploratory study confirms these experiences and concluded that with ageing PWID spread thinly across older adult services, which usually provide little staff training and contact with ID specialists, their specific ID needs remain unmet.

Focus group participants discussed their dilemma as to how to support a client in the later stages of their dementia as well as when to move someone who can no longer stay or cope in their home. They discussed being unsure of what constitutes best practice. Wilkinson et al., (2004) suggest that although staff, managers, service providers and purchasers prefer the idea of supporting people to 'age in place', whereby the client remains in their own accommodation with support, there are significant drawbacks. From their study they found that with one exception, none of the organisations had experience of providing end stage care and many clients were referred out to generic services when staff became overwhelmed with their care needs, a move perceived to be detrimental to the client. The paucity of care management research to guide ID clinicians is striking and is perhaps another example of how cross cutting dialogue with older adults services may be beneficial, as examples of best practice have been published, for example evaluating quality of life using the principles of Dementia Care Mapping.
Participants also observed that many day centres were often inappropriate for ageing clients with ID and that loss of day services can be detrimental to a client’s wellbeing. Both focus groups discussed their concerns that as ageing clients’ needs change they require a different programme and currently services are unable to respond. Participants spoke of the philosophical shift that needs to occur if ageing clients are to receive appropriate day services. For example, many centres have adopted a normalising agenda and have operationalised the concepts embedded in Valuing People (Department of Health, 2001a) such as choice, independence and inclusion. Participants argued that a programme that advocates new learning and moving towards independence may be suitable for an adult in their 20’s but less so for an adult in their 50’s who may prefer a different pace of activity and may be much less concerned about achieving greater independence. Participants spoke of wanting day services to accommodate these changing needs, not just when someone has dementia but as increased sensory and mobility problems manifest as someone ages.

With ageism prevalent across many strata of society (Allen, 2006), PWID face a double challenge as they age. One participant in this study commented there has been a history of infantilising PWID and that as a client ages those involved with their care, professionals and family alike, have to confront their own assumptions and prejudices about ageing as well as having an ID. Furthermore the lives of PWID frequently deviate from the usual trajectory of life cycle stages (Vetere, 1993) and later transitions such as retirement may not be viewed as relevant, or for those PWID who are working discussions about pensions may be overlooked. Therefore it is hardly surprising to find
clinicians and staff struggling to conceptualise ageing in this cohort as models of normal ageing do not capture a PWID’s experience.

**Methodological Issues**

The small number of participants responding to the questionnaires limits the strength of the conclusions that can be drawn. However, the study did receive replies from across the UK, from psychologists in different stages of their career and from a variety of health care trusts thus reflecting a diverse range of views. The low response rate may be due to a discrepancy between the very high research interest in this area and the reality faced by clinicians. While we expected this area to be a relevant concern to clinicians, clinical psychologists in ID services tend to be ‘jack of all trades’ and may have little experience of assessing PWID for dementia. Another potentially more worrying reason, is that clinicians are unaware of the issues for aging PWID and do not feel it warrant attention.

The study may also be limited by the use of a questionnaire survey, which relies on self report of practice and does not involve objective measures. The design of the questions could be improved to clearly differentiate out the practice for prospective baseline assessments and retrospective dementia assessments. It is unclear from the current questionnaire what type of assessment respondents referred to in their answers. Although tools for prospective and retrospective assessments may not differ widely, the conversations clinicians have with clients and carers are likely to differ.
As with ID and ageing research this study primarily focused on meeting the needs of people with Down’s syndrome and dementia. It would have been useful to include a section in the questionnaire to ascertain whether clinicians have seen PWID without Down’s syndrome for an assessment of dementia, either prospectively or retrospectively as PWID without Down’s syndrome are at risk from developing dementia albeit with a later onset, at a similar rate to that found in the general population (Zigman et al., 2004). It can be hypothesised that similar difficulties would be encountered when conducting assessments.

The strength of the study manifests from the focus group data. These participants, although self selected and from services where examples of excellence can be found, highlighted the ongoing difficulties in meeting the needs of this client group. Despite being very knowledgeable of the current literature and mostly having considerable clinical experience with this cohort, the participants had yet to resolve the dilemmas and issues arising from assessment and intervention. It could be hypothesised that less experienced and less informed clinicians may be struggling to deliver a service, if at all, to this cohort. More worryingly clinicians may not have given as much thought to these dilemmas or be aware of the recommendations made in the literature.

**Conclusion**

There seems to be a clear need for changes nationally and locally to address the current gaps and shortfalls in service provision. The results suggest that without strategic planning and funding, services will continue to be fragmented and unable to meet the needs of this group. Research is urgently required regarding the assessment of dementia
and subsequent intervention, particularly research aimed at improving the reliability and validity of assessment tools as well as research exploring clinicians’, carers’ and clients’ experiences of disclosing a diagnosis of dementia. This study also highlighted the need for cross cutting dialogue between older adult and ID services, to share research and information. Such research would enable the development of explanatory models and guidelines of best practice to be developed and implemented. Currently, without empirical evidence to guide them, clinicians are given little choice but to meet the needs of this cohort in a less than satisfactory way.
References


UK


Critical Appraisal
Introduction

In this critical appraisal I will focus on the methodological issues that arose whilst conducting this study, comment on the clinical implications and the research areas that still need to be addressed and provide some personal reflections on issues that arose for me throughout the study.

1. Methodological Issues

In designing this study I felt a questionnaire would capture opinions from a wide source whereas focus groups would allow an opportunity to explore issues in depth. There are a number of points that arose from these decisions and warrant further discussion.

1.1 Response rate

In thinking about how to sample participants for this study I chose a target population of clinical psychologists. I assumed, in view of the fact that dementia in people with ID is a "hot topic" in the literature, that clinical psychologists would be very interested in this study and would recognise the need to participate as research is an integral part of their training and practice. Although I utilised two recruitment routes, namely a faculty of ID conference and the faculty newsletter plus sent out two follow up reminders, they yielded a response rate of only 18.2%. I had anticipated difficulties with this methodology, given that Dillman (2000) has reported research, using postal questionnaires, often has around a one-third non response rate and that non-responders usually differ considerably from responders e.g. in terms of education, interest and motivation. I was surprised, however, at the poor response rate in this study. As clinical psychologists have equivalent levels of education due to similar training criteria, I
believe that difference in levels of interest and motivation must account for the
responders and non-responders to this study. On reflection I might have been able to
improve the response rate by attending the faculty conference myself to promote the
study in person. Instead I had to rely on a colleague who was enthusiastic and supportive
of the project but was unable to dedicate the time to promote and chase up participants.

1.2 Research topic

Despite increased research interest in ageing with ID, the poor response may also have
been due to an over-estimation of clinical interest in ageing issues. As the focus groups
highlighted, a clinical psychologist specialising in ID is often required to be a “jack of
all trades”, working with adults from 18 years with a wide range of ID presentations.
Although ageing is an important and arguably a current topic of interest, it could be
hypothesised that other issues may be more pressing to a clinician and the service they
work for, such as transition issues arising from moving an adolescent with ID to adult ID
services or working with individuals who display challenging behaviours. Demographics
may also play a part in the poor response. One focus group participant commented the
numbers of ageing clients in their catchment area were very small compared to the
number of younger adults. It could be hypothesised, therefore, that if one was working
predominantly with ageing adults with ID then you might have more to say on the issues
of ageing and arguably would be more motivated and interested in participating in
research focusing on ageing and ID, than if one works predominantly with younger
adults.
1.3 Participants issues

Some of the ID services contacted had more than one psychologist and although participants were actively encouraged to complete their own questionnaire often only one was returned on behalf of all the psychologists in the service. This was understandable given the clinical demands on clinicians however, it is unlikely that each psychologist conducts their assessments in the same way, particularly the conversations they have with the client and carers. I also had questionnaires returned stating that the respondent had not seen any clients for a dementia assessment in the past year which I found surprising and left me wondering whether in some localities a psychological assessment is not treated as an integral part of a broader dementia assessment. If more time had been available I would have liked to have explored this further, particularly participants’ views on why they had not seen any clients, who was managing this client group in their area and exploring whether they had considered implementing baseline screening on their younger cohort.

1.4 Prospective or retrospective assessments

Following the return of the questionnaire it was evident that additional questions might have yielded useful data. Firstly, a question clarifying the type of referral received by the service would have enabled me to ascertain whether respondents were discussing a referral for a prospective assessment, such as a baseline screening or a retrospective assessment for dementia. Although the list of assessment tools may not differ widely for these types of assessments, the conversations that clinicians have with clients and carers regarding the purpose of the assessment, may do. It was apparent from the focus group discussions that there was an unease discussing the purpose of the prospective
assessment and that an element of subterfuge may occur. Participants spoke of actively holding back information from clients, and to a certain extent carers, regarding the higher risk of dementia in people with Down’s syndrome, preferring instead to frame the reason for conducting a prospective assessment in terms of monitoring changes as one grows older. Most participants expressed similar sentiments as to why they withheld this information, when conducting a baseline assessments, namely out of fear of causing undue upset and distress, uncertainty in diagnosis and querying whether the client would understand.

One focus group discussed in depth whether a screening for dementia is similar to other health screenings such as cervical screening. Although such screenings involve very different procedures some participants felt the process was similar, for example, one is called to a screening because one has been identified to be at risk from developing a disease. One is then monitored over a number of years and if an abnormal result arises, further testing is initiated and if necessary treatment is given. A question included in the questionnaire clarifying the nature of the referral would have been enabled me to see if conversations explaining the purpose of the assessment do differ between prospective and retrospective assessments.

1.5 Feedback to clients

Finally an additional question in the feedback section may have yielded interesting data. 20% of respondents stated they did not give feedback to clients and I am curious to know why this is. An open ended question would have given an opportunity for respondents to expand on their reasons although, I am mindful that the questionnaire
utilized in this study was already lengthy and adding questions, although interesting, may have made the document more laborious to complete.

1.6 Quantitative data analysis

Whilst reflecting on the analysis conducted in this study I was aware that content analysis has been criticised as a methodology. Content analysis is appealing because it offers a model for systematic qualitative analysis. However, criticism has been levelled at this approach, namely that the results generated have been judged ‘trite’ when researchers rely exclusively on frequency outcome measures, ignoring the meaning of the content (Joffe & Yardley, 2004). In an attempt to avoid the data appearing ‘trite’, the responses to the open ended questions, in this study, were coded for their frequency providing the reader with an overview of most frequently occurring themes. These themes then formed part of the interview schedule for the focus group, giving me an opportunity to explore the meaning of participants’ responses.

1.7 Qualitative Analysis

When deciding which analysis to use for the focus group, I originally chose Interpretative Phenomenological Analysis (IPA) given the wide use of this methodology in the qualitative literature. However, upon commencing the analysis it became clear that my data did not lend itself particularly well to this methodology. IPA is an inductive form of analysis and is phenomenological in that it is concerned with eliciting and exploring individual, personal accounts of an experience. But it is also ‘interpretative’ as it involves the researcher’s own interpretation of the data. The focus group schedule asked questions on practice and service issues that yielded descriptive data on the
current picture of service provision. Other questions asked about clinicians’ experiences of disclosing a diagnosis, yielding data that reflected personal and professional dilemmas. Overall the data could be viewed as comprising of experiential and factual data. Following much debate with my supervisor and experienced qualitative researchers, it was decided that Thematic Analysis would be better suited to this type of data as it would allow me to combine analysis of codes (i.e. how many people mentioned validity and reliability of assessment tools) with analysis of their meaning (i.e. the impact of not having reliable tools undermining the clinicians confidence in their diagnosis).

1.8 Focus group process

Running the focus groups was a challenging but enjoyable process. Despite warnings that it may be difficult to maintain control and keep participants focused on the topic or they may require prompting to talk, I did not encounter these problems. Participants were keen to contribute and gave articulate and interesting views although, at times, I had to remind them of the purpose of the question and keep them on track. I think this was helped by the participants being well educated who are use to articulating their views in public settings such as clinical meetings; I imagine it would be a very different process with more socially inhibited and less articulate participants. Transcribing the discussions was probably the most arduous part of conducting the groups as you are not transcribing just one participant’s views but five or six. Many of the participants would cut across other participants making it difficult to track who was speaking. Luckily I had the fore sight to map where participants sat and could picture who was speaking when transcribing.
2. Clinical Implications

2.1 Strength of the study

In terms of the study's strength, the questionnaire and the focus group results contribute rich and interesting data to an otherwise scant body of empirical research. Unlike the older adult literature, there is a paucity of literature on clinical and ethical issues when working with an ageing ID cohort. This study has highlighted just how difficult some of these clinical and ethical issues involved in such work are to resolve. The focus group participants were on the whole highly experienced and motivated clinicians and were up to date with current literature and recommendations, yet they struggled to reach a consensus on issues of assessment and intervention of PWID and dementia. One queries how less experienced and less informed clinicians meet the needs of ageing clients with ID, if at all. This query warrants further research as it could be hypothesised that the needs of many ageing clients with ID remain unmet and possibly ignored.

This study's initial findings give a very useful picture of current practice and shortcomings and provide a pilot study from which a more substantial body of work could be launched. The questionnaire could be re-designed to incorporate the additional questions suggested as well as steps taken to improve the validity and reliability. If I was to conduct this study again I would consider the merits of using an internet-based questionnaire, utilizing HTML and data-based technology. It would enable me to set up the questionnaire online and participants could complete the questionnaire and email it back. This technology may increase the response rate as email and internet based technology are widely used in the workplace and home plus it may reduce the risk of a questionnaire being misplaced. Finally, further funding could be sought to enable more
focus groups to take place and further explore clinicians experiences of working with this client group.

3. Future research directions

As discussed in the empirical paper, this study has raised a number of research issues that need addressing in future studies. Along with improving diagnostic criteria for dementia in PWID with and without Down’s syndrome and an increase in standardised tools with good reliability and validity, there are also clinical and ethical issues arising from the assessment, intervention and subsequent care management that still need to be addressed. I have also been struck, when surveying the literature in preparation for this study and whilst conducting it, that there are a number of areas which require urgent research attention if the management of dementia in PWID is to be improved. These areas will now be discussed.

3.1 Older Carers

An important point in understanding the perspective of older family carers of PWID is to recognise how little has changed for them over many years; their lives continue to revolve around caring for their relative. There has been little progress on meeting the huge shortfall in residential options outside the family home; thus for many families there are very few options other than continuing to care for their relative at home. In England, local authorities are now expected to prioritise older family carers (Department of Health, 2001a) and this includes identifying all family carers over the age of 70 years old and facilitating person-centred planning for their relatives with ID which addresses futures plans. Older carers have already cared for their child or relative for many years
and at a time when their resources and energies begin to deplete due to their own ageing, their child's or relative's care needs may increase dramatically to their developing dementia. Research has found that many carers do not want their living arrangements to change dramatically but rather they would prefer additional support in order to cope with caring for their child or relative (Thompson, 2001). Urgent research is needed into how services can best assist older carers and provide a range of options such as respite.

3.2 End of life issues

As the progression of Alzheimer's disease in adults with DS is much quicker than among those in the general population affected by the disease, often with a brief duration of 2-8 years, the end stage is reached much sooner (Prasher & Krishman, 1993). Palliative care involves the control of pain and other symptoms and aims to achieve the best quality of life for the person and their families (Watchman, 2005). Currently there is a paucity of research into models of delivering palliative care for PWID and dementia, such as accessing mainstream palliative care services, as well as little understanding of the wishes of PWID and their families in managing this end stage of dementia. There are also great differences in how death and end-of-life care is perceived by different cultures. Research is needed into understanding these cultural differences so that guidance can evolve on culturally sensitive palliative care. Finally practical issues have been woefully neglected. Watchman (2005) identified from her study exploring practitioners' views of end-of-life care for PWID and dementia that procedures or guidelines were not in place for working with someone who is dying, only procedures for what to do once the death had occurred.
3.3 Pain management

As is the case in the general population, where there is a recognised under-reporting and under-treatment of pain in those with dementia, the pain management needs of PWID often not attended to. Wilkinson, Kerr, Cunningham and Rae (2004) identified, based on their evaluation of homes providing care for PWID and dementia, that medication may not be given for pain management when it is required. Wilkinson et al., (2004) identified a lack of training underpinned these decisions as staff were not aware of the interaction between pain, dementia, and ID. Yet Edwards et al.'s (2001) study with nurses working with people from the general population, found that with appropriate training there can be a significant improvement in people’s pain experiences. Research is urgently needed on pain management in PWID and dementia enabling guidelines to be implemented on how to recognise and manage pain in this cohort.

3.4 Dementia-friendly environments

When thinking about the home a person with dementia, with and without ID, lives in, it is important that the environment is enabling the person rather than disabling them further. Although guidelines on developing dementia-friendly environments for PWID have been published (Hutchings, Olsen & Ehrenkrantz, 2000), Wilkinson et al., (2004) found, with a few notable exceptions, that current and future planned accommodation options appear to pay little regard to these important recommendations. Worryingly, they found staff often responded to challenging behaviours induced by inappropriate environments with medication, when simple modifications to noise, light, colours and signage would likely have reduced these challenging behaviours. There is a
need for more literature on the impact of built environments on PWID who develop dementia.

3.5 Experiential Issues

Researchers have begun to look at experiential issues such as living with a person who has dementia and ID (Lynggaard & Alexander, 2002), staff experiences of end of life care (Watchman, 2005), yet far more studies are needed. This study highlighted the similarities in dilemmas arising from disclosing a dementia diagnosis to PWID and older adults in the general population but further research is needed to see if this is a finding that generalises to other clinical psychologists through conducting more focus groups as well as extending it to other professions such as psychiatrists and nurses specialising in ID, as has been the case in research from the older adult field. I am also interested in PWID’s experiences of ageing and living with conditions such as dementia as well as thinking about how carers and services currently respond to other age related conditions such as Parkinson’s disease as the emphasis tends to be placed on dementia. All these areas have yet to be explored and this needs to be remedied because without this research it is difficult to develop protocols and guidelines on these issues.

3.6 A Different perspective

One of my thoughts throughout this study has been the potential linking up of previous research conducted in both ID and older adult fields. Wilkinson and Janicki (2005) have recently highlighted this point and argued that with the mirroring of increased life expectancy, health and social care needs in both the ID and general populations, the potential for crosscutting dialogue is enormous. One area where this may easily take
place is with person centred planning (PCP). PCP is utilised in ID work for many years and aims to improve the quality of life for the individual by addressing their unique needs and wishes. In recent years, in the older adult field, there has been philosophical shifts in dementia care, driven by Tom Kitwood and colleagues of the Bradford to adopt person centred approaches to dementia care, namely addressing the psychosocial and personhood dimensions of clients' experience of dementia. Where care providers have adopted a PCP approach in dementia care, the research has shown that more interaction and of higher quality, a decrease in depression and a lower rate of general decline can occur (Murphey, Lindesay & Dean, 1994). Kitwood also introduced the concept of 'rementing' which refers to the recovery of cognitive and emotional well being when a person's needs are met.

These ideas of 'rementing' and using PCP approaches in dementia care could be utilised in ID services, particularly as a PCP culture already permeates adult ID service provision, enabling clinicians and carers to address the personhood of a PWID and dementia. Equally Dementia Care Mapping devised by Kitwood (1997) to address personhood of clients in residential settings, offers a systematic evaluation of care provision and would assist those in the ID field with evidence of models of good practice. In return the ID field has a history of tested technologies and community support practices that can be further refined and applied to people in the general population affected by cognitive impairment, for example the use of small neighbourhood group homes as advocated by Janicki, Dalton, McCallion, Baxley and Zendell (2005) in the U.S.A. Ideally I would like to see the ID and older adults fields learn from each other, through crosscutting dialogue. A universal approach may evolve
towards older age problems and care that can be adapted, when needed, to account for the additional needs arising from living with an ID.

4. Personal reflections

As an educated adult without ID I do not know what it is like to live with an ID and would need to make informed assumptions about the difficulties and differences that PWID encounter in their daily lives. However, I am ageing and this study has raised a number of issues for me about my future as an older person, possibly needing care.

4.1 Positive models of ageing

Whilst on my older adult placement and through conducting this study I was struck by the apparent absence of positive models of ageing, even more so for women. Older role models are few and far between in society, rather there is a media and societal emphasis on the merits of being youthful. When older adults do appear in the media they are often presented for comic effect and not respected. My impression, as I age, is that current society appears not to value the contributions older citizens can make. Throughout this study I have reflected frequently on the ‘double whammy’ a PWID faces as they age. Current society has yet to acknowledge and value the contributions a younger adult with ID can make, for example, in terms of employment and parenting, let alone begin to consider what an ageing PWID may offer society. Therefore a ‘double whammy’ of prejudice of ageing and ID exists. A fundamental shift in attitudes towards ageing needs to occur before older adults with and without ID can be treated with equity, dignity and respect and not face prejudice on the basis of disability and age.
4.2 One size fits all

Currently there appears to be a ‘one size fits all’ approach to older adult day services and accommodation with an emphasis on homogenising people’s tastes, views and activities. For example when on an older adult placement I visited a number of homes, and residents programmes were not individualised therefore everyone had to watch the same television programme or complete the same activity. This I found very disconcerting as I could not imagine how I would fit into a programme that did not take into account the views and tastes I had developed over a number of years prior to moving into a home. In recent years within the ID field, there has been a movement to respect the heterogeneity of peoples’ tastes and views. With PCP approaches and direct payment schemes being employed PWID and their carers are being encouraged to choose the service that will suit their needs. For example paying for a person to support trips to community leisure services rather than attending the day centre. I hope that this recognition of the heterogeneity of people’s needs, views and tastes will become more commonplace in services for older adults with increased crosscutting dialogue between ID and older adult services.

Fragility of ageing

This study touches on many aspects of ageing, in particular developing dementia. In my contact with people with and without ID who have developed dementia I have encountered a range of negative attitudes, with a few notable exceptions, from carers and family members towards the person with dementia. One way of formulating these negative attitudes is to use a psychodynamic perspective and to think about the defenses one puts in place to avoid dealing with the veracity of ageing. It is easier to dehumanise
the person with dementia rather than face the reality that oneself will get older and be at risk of developing dementia. We are often afraid of becoming frail and highly dependent and it will be felt more acutely if one is living in a society that has communities plus a media and societal emphasis on being youthful and independent. For care staff, death of a resident can be a drawn out process and contact with those who are elderly, weak and vulnerable may activate fears of becoming dependent ourselves, as well as fears about being lost in confusion. These thoughts may be terrifying and threaten our basic sense of security.

It was a relief to encounter some carers and clinicians during my older adult placement who adopted a very different view of ageing, in particular with dementia. They advocated the ideas of Tom Kitwood (2001) and Graham Stokes (2002). Both these practitioners adopt a person centred approach to ageing, arguing that the person needs to be understood before the dementia. Without this understanding the dementia will impact more severely and in some cases more rapidly. It gave me hope that as I age, services will develop, acknowledge and value the person first and that I and in the later stages other people will be able to manage my needs with dignity and respect.

5. Conclusions

Conducting this study has given me the experience of utilising both quantitative and qualitative methodologies as well as afforded me opportunities to explore dilemmas and opinions with experienced clinical psychologists and highlighted issues I will myself encounter on completing my training. This study, keeping in mind the limitations highlighted, goes some way to demonstrating clinical psychologists’ clinical and ethical
experiences in meeting the needs of ageing PWID. This study has highlighted ongoing
difficulties in assessment, intervention and subsequent care management of PWID and
dementia and how far research and clinical practice need to evolve in order to meet the
needs of this ageing cohort more effectively. There remain many areas yet to be
explored and understood with regard to issues of ageing with an ID.
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Appendices
Appendix 1

Questionnaire
Dear Delegate

We are writing to request your assistance with a timely study into service provision for people with learning disabilities and possible or diagnosed dementia, in particular those with Down’s syndrome. We are hoping to develop a real-life picture of what services are currently doing to meet the needs of people with Down’s syndrome at risk of developing dementia. Despite a growing evidence base of good practice regarding assessment and care management, service provision in the UK appears variable. We are keen to find out what is actually provided in different areas and would be grateful if you could spare a few moments to complete the attached questionnaire. More than anything we are hoping to obtain an honest picture of what goes on in the real world of clinical services, not what clinicians think they should be doing. Therefore your honesty is greatly appreciated and we would like to assure you that your answers will be treated with utmost regard for confidentiality. We estimate that the questionnaire will take approximately one hour to complete.

This study has been approved by an NHS ethics committee and we are bound by regulations on confidentiality and storage of data. All data will be anonymised to prevent identification of your participation and will only be seen by Ellen McGuire and her supervisors. Ellen McGuire is the chief investigator and a Trainee Clinical Psychologist conducting this study as part of a Doctorate in Clinical Psychology. Ellen is supervised by Dr Katrina Scior, Lecturer in Clinical Psychology on UCL doctorate in Clinical Psychology and Clinical psychologist with Newham Primary Care trust and Dr Karen Dodd, Head of Psychology Services for Surrey Oaklands Trust and Consultant Clinical Psychologist for Learning Disabilities. By reading this letter and deciding to complete the questionnaire, your participation will be assumed to signal your consent to taking part in the study.

We are also hoping to run some focus groups, as very little research has been conducted into clinical psychologists’ experiences of working with this client group. This is in contrast to the older adults population, where extensive research has been conducted into the issues faced by various professionals, such as disclosing diagnosis, working with carers and staff, as well as working with the clients’ experience of dementia and the use of person centred planning. In the focus groups we are interested to explore in some depth practices, ideas, beliefs and values psychologists experience when working with people with Down’s syndrome and possible dementia and to what extent these are similar or different to those encountered by psychologists working in older adult settings. If you would consider being part of a focus group please indicate this in the details section of the questionnaire. Focus groups would meet on a one-off occasion for
1 ½ to 2 hours at a location convenient for participants. An information sheet and consent form will be sent following the receipt of your details.

We hope this study will contribute to the evolving field of working with Down’s syndrome and dementia and the results will give clinicians an idea of what other services are encountering.

Thank you for taking the time to read this and we look forward to receiving your questionnaire shortly.

Yours Faithfully

Ellen McGuire  Dr Karen Dodd  Dr Katrina Scior
(Trainee Clinical Psychologist  (Head of Psychology Services  (Lecturer in Psychology
UCL Doctorate in  Surrey Oaklands Trust)  UCL Doctorate in
Clinical Psychology)
A Study Into The Service Provision To People With Down’s Syndrome and Possible Dementia

Thank you for agreeing to take part in this research. The purpose of this questionnaire is to ascertain what clinical psychologists are currently doing to meet the needs of people with Down’s syndrome at risk of developing dementia. As stated in the information letter we are interested in capturing the real world of clinical services rather than what clinicians think they should be doing. We hope to gain an understanding of the dilemmas and issues that clinicians face when assessing and offering follow-up for this client group and your honesty is greatly appreciated. The information given in the details section is not compulsory other than if you would like to be involved with the focus group, however it would be beneficial for tracking the questionnaires. Your responses will be treated with the utmost confidentiality and will be anonymised for the analysis. It is estimated that completing this questionnaire will take no more than an hour of your time.

Once the questionnaire is completed please send to Ellen McGuire c/o Sub Dept. Clinical Health Psychology, UCL, Gower Street WC1E 6BT. If you have any queries regarding this questionnaire or would like to discuss this research further, please contact us at ellenmcguire@btinternet.com and/or k.scior@ucl.ac.uk.

Thank you for your participation in this research and we look forward to receiving your questionnaire shortly.

Ellen McGuire  Dr Katrina Scior  Dr Karen Dodd

<table>
<thead>
<tr>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name</td>
</tr>
<tr>
<td>NHS Trust</td>
</tr>
<tr>
<td>Years since qualification</td>
</tr>
<tr>
<td>Number of psychologists in post in your service</td>
</tr>
<tr>
<td>Wte of Psychologists in post in your service</td>
</tr>
<tr>
<td>Preferred contact method (only complete this if you would be willing to participate in a focus group)</td>
</tr>
<tr>
<td>Email</td>
</tr>
<tr>
<td>Telephone</td>
</tr>
<tr>
<td>Address</td>
</tr>
</tbody>
</table>
**Referral**

This section asks about the referral process for clients with Down’s syndrome and possible dementia.

1. Are you aware how many referrals your service received over the past year requesting an assessment of a client with Down’s syndrome and possible dementia?
   - Yes □
   - No □ go to question 2

If yes how many referrals over the past 12 months? ...........................................................

2. Where did these referrals originate from? If possible please give approximate numbers or percentages for each referral source.
   *(Please tick from the following options)*

<table>
<thead>
<tr>
<th>GP</th>
<th>Other disciplines within the CLDT* (please specify)</th>
<th>Residential home staff</th>
<th>Day centre</th>
<th>Family</th>
<th>Care Manager</th>
<th>Other (please specify)</th>
</tr>
</thead>
</table>

*CLDT refers to Community Learning Disability Team

3. What is the waiting time between receipt of referral and start of the assessment?

Minimum _____ weeks/ months (please circle)

Maximum _____ weeks/ months

**Pre-Assessment**

This section refers to the first appointment and focuses on who is invited, the possible reasons for this decision and how the purpose of the assessment is explained.

4. Who is routinely talked to about the purpose of the assessment? Please answer for each in turn. *(Please tick from the following options)*

<table>
<thead>
<tr>
<th>Client</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Mostly</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Client’s family</td>
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<td></td>
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<tr>
<td>Paid carer</td>
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<tr>
<td>Others CDLT members (please specify)</td>
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<tr>
<td>Other (please specify)</td>
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</tbody>
</table>
5. How is the purpose of the assessment explained to the client prior to the assessment? What are the key points of your preamble, for example, explaining why they have been referred or what they will be expected to do?

5a. How is the purpose of the assessment explained to the carer prior to the assessment? What are the key points of your preamble?

6. Do you, at least sometimes, explicitly use the term ‘dementia’ when explaining the purpose of the assessment?

Yes □ go to question 6a  Never □ go to question 7

6a. If you do use the term dementia, at least sometimes, who would you use it with? Please answer for each in turn. (Please tick from the following options)

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Mostly</th>
<th>Always</th>
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</thead>
<tbody>
<tr>
<td>Client</td>
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<tr>
<td>Client's family</td>
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<td></td>
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<tr>
<td>Paid carer</td>
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<tr>
<td>Others (please specify)</td>
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</table>

Now go to question 8

7. If you do not use the term dementia, either never or not with some parties, what terms do you use?
7a. What are some of your reasons for using these other terms and not the explicit use of 'dementia'?

The Assessment

This section refers to the process of assessing an individual with Down’s syndrome for possible dementia. This does not reflect what a clinician should be doing but rather reflects the wide range of tools that one could possibly use.

8. When considering the client’s current physical health what routine screens does your service complete? (Please tick from the following options)

<table>
<thead>
<tr>
<th>Routine Screen</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Mostly</th>
<th>Always</th>
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</thead>
<tbody>
<tr>
<td>Thyroid check</td>
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<tr>
<td>Sensory Impairment (Vision)</td>
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<tr>
<td>Sensory Impairment (Hearing)</td>
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<td>Seizure activity</td>
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<td>General health screen</td>
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<td>MRI scan</td>
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<td>Others (please specify)</td>
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</table>

9. What tools do you use for the direct/indirect assessment of cognitive functioning and decline? (Please tick from the following options)

<table>
<thead>
<tr>
<th>Cognitive Assessment Tool</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Mostly</th>
<th>Always</th>
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</thead>
<tbody>
<tr>
<td>DMR (Dementia questionnaire for mentally retarded people)</td>
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<td>DSDS (Down Syndrome Dementia Scale)</td>
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<td>Oliver &amp; Crayton</td>
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<tr>
<td>Bournewood</td>
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<tr>
<td>WAIS III</td>
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<tr>
<td>BPVS (British Picture Vocabulary Scale)</td>
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<td>Schonell</td>
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<tr>
<td>Rivermead Behavioural Memory Test</td>
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<tr>
<td>Others (please specify)</td>
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</table>

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10. What tools do you use for the assessment of the client's functional skills? (Please tick from the following options)

<table>
<thead>
<tr>
<th>Tool</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Mostly</th>
<th>Always</th>
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</thead>
<tbody>
<tr>
<td>Adaptive Behaviour Assessment system</td>
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<tr>
<td>Adaptive Behaviour Scales (ABS)</td>
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<tr>
<td>Vineland</td>
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<td>HALO</td>
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<tr>
<td>Others (please specify)</td>
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</table>

11. What tools do you use for the assessment of possible emotional and environmental factors? (Please tick from the following options)

<table>
<thead>
<tr>
<th>Tool</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Mostly</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reiss Screen for Maladaptive Behaviour</td>
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<tr>
<td>PASS-ADD</td>
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<tr>
<td>Holmes-Rahe Life Event Checklist</td>
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<tr>
<td>Others (please specify)</td>
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</tbody>
</table>

12. Do you routinely take a full history from the carer, in addition to completing these formal assessment tools? Please tick.

Yes □  Sometimes □  No □  go to question 14

13. What areas to you routinely assess with the carer? (Please tick from the following options)

<table>
<thead>
<tr>
<th>Area</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Mostly</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eating abilities</td>
<td></td>
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<tr>
<td>Drinking abilities</td>
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<tr>
<td>Nutrition</td>
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<tr>
<td>Sleeping</td>
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<tr>
<td>Mobility</td>
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<tr>
<td>Depth perception</td>
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<tr>
<td>Others (please specify)</td>
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</table>

Please now go to Q14

14. If some of the above areas (questions 8-13) are not routinely targeted in your assessment can you please give some reasons for this, e.g. assessment tools not available?
Post-Assessment

This section refers to what happens once the assessment has been completed. We are interested in the process of disclosing/not disclosing the results, any probable diagnosis of dementia and how such feedback is given, if at all?

15. Do you routinely give feedback to the referrer?
   
   Yes □  go to question 15a   No □  go to question 15b

15a How is feedback to the referrer given?
   (Please tick from the following options)

<table>
<thead>
<tr>
<th>Face to face</th>
<th>By telephone</th>
<th>Written</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

Please now go to Q15b

15b How is feedback to the client given?
   (please tick from the following options)

<table>
<thead>
<tr>
<th>Not given to client</th>
<th>Face to face</th>
<th>By telephone</th>
<th>Written</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Go to Q15c</td>
<td>Go to Q15c</td>
<td>Go to Q15c</td>
<td>Go to Q15b</td>
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</tbody>
</table>

15b. If you routinely copy the results of the assessment to the client is it in
   
   a) the same format given to other people such as the referrer? □

   b) in a modified format designed for the client’s level of understanding? □

15c. Who else do you give feedback to about the assessment outcome?
   (Please tick from the following options)

<table>
<thead>
<tr>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Mostly</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Client’s Family</td>
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<tr>
<td>Paid carer</td>
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</tr>
<tr>
<td>GP</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (please specify)</td>
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</tbody>
</table>

15d. How is this feedback given? (Please tick from the following options)

<table>
<thead>
<tr>
<th>Face to face</th>
<th>By telephone</th>
<th>Written</th>
<th>Other (please specify)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Client’s Family</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Paid carer</td>
<td></td>
<td></td>
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<tr>
<td>GP</td>
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<td></td>
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<tr>
<td>Other (please specify)</td>
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</table>

..........................
16. In cases where the outcome of your assessment points to probable or definite dementia, who is this disclosed to? If this has not yet occurred in your practice, please give your most likely response should you identify signs of probable or definite dementia. 

(Please tick from the following options)

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Mostly</th>
<th>Always</th>
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</thead>
<tbody>
<tr>
<td>Client</td>
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<tr>
<td>Client's Family</td>
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<tr>
<td>Paid carer</td>
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<tr>
<td>GP</td>
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<tr>
<td>Other CDLT members (please specify)</td>
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</tbody>
</table>

17. The following statements originate from professionals working in Older Adult settings and refer to the perceived benefits of disclosing a diagnosis of dementia to the client and their family. Can you please rate your agreement/disagreement with the statements in light of your practice and experience of working with people with Down's syndrome and possible dementia? (Please tick from following options)

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly disagree</th>
<th>Mildly disagree</th>
<th>Neither agree or disagree</th>
<th>Mildly agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disclosure facilitates future planning</td>
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<tr>
<td>Disclosure brings psychological benefits to the client and/or carers</td>
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<tr>
<td>Client/ carers have a right to know</td>
<td></td>
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<tr>
<td>Disclosure maximises treatment options</td>
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<tr>
<td>Disclosure makes it easier to obtain a second opinion</td>
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<tr>
<td>Disclosure allows client and family to make the most of opportunities</td>
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</tbody>
</table>
18. The following statements or issues originate from professionals working in Older Adult settings and refer to the perceived risks or disadvantages of disclosing a diagnosis of dementia to the client and their family. Can you please rate your agreement/ disagreement with the statements in light of your practice and experience of working with people with Down’s syndrome and possible dementia? (Please tick from following options)

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly disagree</th>
<th>Mildly disagree</th>
<th>Neither agree or disagree</th>
<th>Mildly agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disclosure may cause undue emotional distress</td>
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<tr>
<td>Clients are unlikely to understand/ retain diagnosis</td>
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<tr>
<td>The costs of disclosure outweigh the benefits</td>
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<tr>
<td>Diagnosis is unhelpful due to a lack of effective treatments</td>
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<tr>
<td>There is a lot of stigma attached to ‘dementia’</td>
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<tr>
<td>Disclosure is unhelpful as often one cannot be confident about the diagnosis</td>
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<tr>
<td>There is a fear of being blamed if diagnosis is inaccurate</td>
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<tr>
<td>Discussing disclosure evokes personal fears regarding aging and death</td>
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<tr>
<td>There is a service culture not to routinely tell people of their diagnosis</td>
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</tbody>
</table>

**Intervention**

This section considers what happens post assessment and whether pharmacological and/or therapeutic interventions are considered.

19. Does your service routinely consider medication to slow deterioration or target specific symptoms?

   Yes □  No □ go to 19a

   If yes, what medication is used? Don’t know □

<table>
<thead>
<tr>
<th>Medication</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Mostly</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Donepizol/Aricept</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rivastigmine/Exelon</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Galathamine/Reminyl</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (please specify)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

19a. If medication is not routinely considered in your service can you give some reasons for this decision, e.g. the client’s psychiatrist is not willing to prescribe?
20. In older adult settings a client and/or carer may receive other interventions alongside medication. Can you please indicate if your service routinely offers any of the following? This list reflects the range of possible interventions on offer, not what should be offered. (Please tick from following options)

<table>
<thead>
<tr>
<th>Therapy or Counselling for client</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Mostly</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Therapy or Counselling for client's family</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Therapy or Counselling for paid carer</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Reality Orientation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Cognitive stimulation</td>
<td></td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>Staff Training</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psycho-education for client</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psycho-education for client's family</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psycho-education for paid carers</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Behavioural programmes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group work</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support Group for fellow service users</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support group for paid carers</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support group for family members</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (please specify)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Thank you for taking the time to complete this questionnaire, we are grateful for your participation in this study and we look forward to receiving your questionnaire.

Ellen McGuire    Dr Katrina Scior    Dr Karen Dodd
Appendix 2

*Ethical Approval Letter*
11 April 2005

Miss Elen J McGuire
Trainee Clinical Psychologist
Clinical Health Psychology Dept
University College London
Gower Street
London WC1E 6BT

Dear Miss McGuire

Full title of study: An exploratory study into the current service provision to people with Down’s syndrome and possible dementia and clinical psychologists specialising in learning disabilities experiences of working with this client group.

REC reference number:

Thank you for your letter of 1 April 2005, responding to the Committee’s request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair together with Dr K Beard and Mrs H Millar.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

The Committee has designated this study as having ‘no local investigators’. There is no requirement for Local Research Ethics Committees to be informed or for site specific assessment to be carried out at each site.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<table>
<thead>
<tr>
<th>Document Type</th>
<th>Version</th>
<th>Dated:</th>
<th>Received:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Application</td>
<td></td>
<td>14/02/2005</td>
<td>14/02/2005</td>
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<tr>
<td>Investigator CV</td>
<td></td>
<td>14/02/2005</td>
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<tr>
<td>Protocol</td>
<td>2</td>
<td>April 2005</td>
<td>04/04/2005</td>
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<tr>
<td>Peer Review</td>
<td></td>
<td>14/02/2005</td>
<td>14/02/2005</td>
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<tr>
<td>Copy of Questionnaire</td>
<td>2</td>
<td>April 2005</td>
<td>04/04/2005</td>
</tr>
<tr>
<td>Letters of Invitation to Participants</td>
<td>2</td>
<td>April 2005</td>
<td>14/02/2005</td>
</tr>
<tr>
<td>Participant Information Sheet</td>
<td>2</td>
<td>April 2005</td>
<td>04/04/2005</td>
</tr>
</tbody>
</table>

Chairman: Professor Patrica Quinn
Vice-Chairman: Dr Malcolm Booth

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Management approval

You should arrange for all relevant NHS care organisations to be notified that the research will be taking place, and provide a copy of the REC application, the protocol and this letter.

All researchers and research collaborators who will be participating in the research must obtain management approval from the relevant care organisation before commencing any research procedures. Where a substantive contract is not held with the care organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

--- Please quote this number on all correspondence ---

With the Committee's best wishes for the success of this project.

Yours sincerely,

pp Professor Patricia Peattie
Chairman

Enclosures: Standard operating procedures
Appendix 3

Focus group interview schedule
Focus Group Schedule

1. The key findings from the questionnaire data suggest an apparent reluctance to use the term dementia with a client both in the pre-assessment phase, where you are explaining about the assessment and the post assessment phase, where you are feeding back the results. There were a wide range of reasons reported and I am interested to hear in more depth your thoughts on some of the reasons for this apparent reluctance?

2. I wonder what you see as the similarities and differences between meeting the needs of an ageing ID population and those in the older adult population?

3. From the questionnaire data there was huge variation in the assessment tools used to assess for dementia and I wondered what your ideas are on why this might be?

4. I am interested to hear about what you have learnt from developing your service to meet the needs arising from working with an ageing ID client group and also what still needs to be addressed in your view?

5. To meet the needs of the ageing general population specialised services have been developed and I wondered what your view was on developing a similar service for ageing ID clients rather than having a generic ID service?
Appendix 4

Consent Form - Focus Groups
CONSENT FORM

Title of study:

Exploring the Practices, Ideas and Beliefs of Clinical Psychologists Specialising in Learning Disabilities When Working With People with Down’s Syndrome and Possible Dementia.

Name of Researchers:

Ellen McGuire
Trainee Clinical Psychologist
UCL Doctorate in Clinical Psychology

Dr Karen Dodd
Head of Psychology Services
Surrey Oaklands NHS Trust

Dr Katrina Scior
Lecturer in Psychology
UCL Doctorate in Clinical Psychology

Please read the following statements and if you agree please initial the box. Thank you.

1. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reasons.

☐

2. I understand that the focus group discussion will be taped and that the data from these tapes will be kept confidential. The tape data will remain anonymous for the duration of the study and will be destroyed once the study is completed.

☐

3. I agree to take part in the above study

☐

...............................  ................  ................
Name of participant Date Signature

...............................  ................  ................
Name of Researcher Date Signature
Appendix 5

An example of initial thematic analysis
Table 1

An example of initial thematic analysis

<table>
<thead>
<tr>
<th>Transcript</th>
<th>Initial themes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>P2</strong> I think from both the understanding of the client, in terms that in fact they are not use to that word and if you try and explain it you have to make reference to other terms like you growing older, your body changing, sometimes find things more difficult, particularly your memory and that you can get help and want to bring in positive things, so there's that side of trying to get the client to understand the term which isn't easy erm but also I suppose <em>yeah a sense of protecting the client from emotional distress</em> particularly in the pre-assessment phase <em>where they actually may not be not be starting the dementing process so you don't actually know</em> so you want to say you are exploring things because they are having some difficulties.</td>
<td>Capacity to understand</td>
</tr>
<tr>
<td><strong>P1</strong> I suppose <em>feel that we are not diagnosticians here anyway</em>, we are clinical psychologists and yes for me if we do find some deterioration, then that's what it is...deterioration. we would then talk to GP's and psychiatrists to investigate further to diagnose to whether someone is dementing so I <em>would feel that be quite cautious</em> because you know I would feel very I don't know, find it difficult to say oh I think your dementing or whatever because I don't think it is my job to say that.</td>
<td>Use of pseudonyms</td>
</tr>
<tr>
<td><strong>P5</strong> and I <em>guess you also another factor might be that all you could ever really say is that someone has got probable dementia.</em></td>
<td>Protecting from distress</td>
</tr>
<tr>
<td><strong>P2</strong> <em>yes absolutely.</em></td>
<td>Professional role?</td>
</tr>
<tr>
<td><strong>P5</strong> it would depend on the client..er..a brain autopsy to finally confirm it, certainly at this stage I think in our knowledge so that also might be a difficulty, but also I <em>am aware as I am saying this that whilst one is more cautious around the client I feel I am perhaps less cautious when we or my colleagues are more certain</em> that someone is showing cognitive decline probably consistent with a diagnosis of Alzheimer's then we do that, we would report that in a report, we would discuss that and describe that in a report really, so there is maybe a kind of discrepancy in how we talk about it, but that is also in terms of thinking who our audience is, <em>who we are speaking to and what capacity they might have</em> and often where we are very certain then the person might, certainly in our experience people who are already declining quite a lot and where actually what you then say need to chose very different words.</td>
<td>Confidence in skills</td>
</tr>
</tbody>
</table>

**Uncertainty**

| **Different standards** One for clients, one for carers |
| Capacity to understand |
Appendix 6

Quantitative Data Tables
<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>S.D</th>
</tr>
</thead>
<tbody>
<tr>
<td>General Health Screen</td>
<td>4.4</td>
<td>.81</td>
</tr>
<tr>
<td>Thyroid Functioning</td>
<td>4.2</td>
<td>.98</td>
</tr>
<tr>
<td>Sensory impairment (Vision)</td>
<td>3.9</td>
<td>.99</td>
</tr>
<tr>
<td>Sensory impairment (Hearing)</td>
<td>3.9</td>
<td>1.1</td>
</tr>
<tr>
<td>Seizure activity</td>
<td>3.7</td>
<td>1.3</td>
</tr>
<tr>
<td>MRI Scan</td>
<td>2.6</td>
<td>1.3</td>
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</tbody>
</table>
### Table B

*Areas of daily functioning routinely discussed with the carer*

<table>
<thead>
<tr>
<th>Area</th>
<th>Mean</th>
<th>S.D</th>
</tr>
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<tbody>
<tr>
<td>Mobility</td>
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<td>.57</td>
</tr>
<tr>
<td>Sleep</td>
<td>4.7</td>
<td>.63</td>
</tr>
<tr>
<td>Eating abilities</td>
<td>4.5</td>
<td>.75</td>
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<tr>
<td>Drinking abilities</td>
<td>4.5</td>
<td>.75</td>
</tr>
<tr>
<td>Nutrition</td>
<td>4.2</td>
<td>1.0</td>
</tr>
<tr>
<td>Depth perception</td>
<td>3.5</td>
<td>1.4</td>
</tr>
</tbody>
</table>
Table C

*Non pharmaceutical interventions*

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Mean</th>
<th>S.D</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff Training</td>
<td>3.8</td>
<td>1.1</td>
</tr>
<tr>
<td>Psycho-education for paid carer</td>
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<td>Psycho-education for family</td>
<td>3.3</td>
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<td>Behavioural programmes</td>
<td>3.2</td>
<td>.84</td>
</tr>
<tr>
<td>Therapy for client’s family</td>
<td>3.0</td>
<td>.91</td>
</tr>
<tr>
<td>Therapy for client</td>
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<td>.94</td>
</tr>
<tr>
<td>Psycho-education for client</td>
<td>2.8</td>
<td>1.1</td>
</tr>
<tr>
<td>Therapy for paid carer</td>
<td>2.7</td>
<td>1.2</td>
</tr>
<tr>
<td>Cognitive stimulation</td>
<td>2.5</td>
<td>1.4</td>
</tr>
<tr>
<td>Reality orientation</td>
<td>2.3</td>
<td>1.0</td>
</tr>
<tr>
<td>Group work for clients</td>
<td>1.8</td>
<td>1.0</td>
</tr>
<tr>
<td>Support group for fellow service users</td>
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<tr>
<td>Support group for paid carers</td>
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<tr>
<td>Support group for family members</td>
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