# Older Irish people with dementia in England

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### **ABSTRACT**

The Irish community is the oldest minority ethnic community in Britain. Despite an older age profile than general or minority ethnic populations, as well as excesses of mental and physical ill-health and socio-economic disadvantage, the age, poor health and social profile of the community is largely ignored by policy makers and providers. Several of these factors predispose the Irish community in England to a higher incidence of dementia. Unlike other minority ethnic groups with growing numbers of people with dementia, the incidence of dementia is already high. Older Irish people are often reluctant to access mainstream services because they fail to recognise their distinct cultural needs and experiences. Irish third sector organisations provide a range of culturally specific services to older people and their carers and increasingly to those with dementia. This article uses data from a mapping exercise which identifies non-governmental services for Irish people with dementia and their carers, explaining what cultural sensitivity means for them. Changes in the UK government and the 'Big Society' agenda pose a threat to dementia services. However prioritising the National Dementia Strategy and revising the National Carers Strategy within this agenda could expand the role of the Irish third sector in England and improve the lives of Irish people with dementia and their carers.

Keywords: Irish; dementia; ethnic elders; informal carers

F or almost a decade now, concerns about the availability, accessibility and quality of services for minority ethnic elders with mental health problems have been raised (RCP 2001; Oomen et al 2009). Since then, the number of

older people from minority ethnic groups has increased and there is evidence that the incidence of dementia and depression has risen also (KCL/LSE 2007; Shah 2008). The National Dementia Strategy (NDS) identifies that

although a third of people with dementia live in care homes, the remaining two thirds live in the community (KCL/LSE 2007). While there is clearly a need for specialised health and social care, there is considerable scope for community facilities which help prevent or delay the onset of dementia and support carers. The decennial census in 2011 will update demographic data, but research into the prevalence of dementia and depression, the availability and uptake of services, especially in relation to people from Black and Minority Ethnic (BME) groups is urgent. BME elders have difficulties getting help and those experiencing dementia have specific needs for services that are sensitive to their culture, language and religious beliefs. The current economic recession and political change geared towards reducing public services pose a threat to this vulnerable group and their carers. However, the 'Building the Big Society' agenda of the coalition government could equally provide opportunities to capture the ability of communities to solve their own problems, save local facilities and even replace state services (Cabinet Office 2010).

This article focuses on older Irish people in Britain, highlighting the invisibility of this community, identifying factors predisposing to a high incidence of dementia and considering what cultural sensitivity means to older Irish migrants. It draws upon the findings of a mapping exercise undertaken by an umbrella organisation representing the Irish voluntary (third) sector in Britain (FIS 2010). This research, which originated in concerns about this increasingly neglected group, involved a survey of third sector Irish organisations and statutory providers. Semi-structured interviews were undertaken with people with memory problems, carers and staff providing advice, advocacy or culturally specific services. With the participants' permission the article is illustrated with excerpts from these interviews. The findings demonstrate the extent to which 'Big Society' already operates within the Irish community and outlines good practice from Irish third sector organisations in the UK. Although

the focus is on Irish people, many of the issues are common to other BME groups in Britain. It is also possible that the invisibility of the Irish in Britain is replicated in other parts of the world where old migrant communities are deemed assimilated and indistinct from the majority population. It is particularly likely when people are not differentiated by skin colour and share the language of the host society. The examples of community engagement and best practice are not unique to the Irish or to British society. The authors acknowledge the problems of diagnosis and different types of dementia (Kitwood 1997), but the term dementia is used in a broad sense to refer to symptoms of memory loss, communication problems, mood and behavioural changes which are experienced in individual ways as a result of specific diseases and conditions. Names of service users, carers and workers have been changed to protect confidentiality.

Despite evidence of an older age profile and multiple disadvantages within the Irish population in Britain (RCP 2001, 2009), there is scant attention by policy makers, researchers and mainstream service providers. With few exceptions (Livingston et al 2001; Sproston & Nazroo 2002) academic research purporting to investigate minority ethnic health and social issues define ethnicity within a skin colour paradigm and focus on visible groups such as Asians or Caribbeans, totally ignoring the Irish (Husain et al 2009) or aggregating them within the White or other White category (Coid et al 2008). This neglect occurs across the spectrum of physical and mental health. The Royal College of Psychiatrists identifies the Irish as a BME community with an older population more than twice the size of the next largest (Caribbean) group, yet no analysis, commentary or recommendations are made (RCP 2009). The Policy and Research Institute on Ageing and Ethnicity similarly demonstrate the Irish population between ages 60 and 79 as double that of the Caribbean and three times greater at 80 and above (PRIAE 2005). However, despite age profile alone being highly predictive of dementia, the Irish community is not discussed and there are no recommendations for action.

These influential documents reflect the general pattern of mainstream and BME policy research and mirror campaigning materials from major lobbying and policy organisations. In contrast, the Irish third sector in different parts of England reports help sought by increasing numbers of Irish people with age related problems and signs or diagnosis of dementia (FIS 2010; Tilki et al 2009). Evidence from these organisations shows that older Irish people and their carers are dissatisfied with or reluctant to access mainstream services largely because they ignore the distinct culture and experience of Irish people. Clearly people have a choice and stigma can prevent some from seeking help. However, it is easy for overstretched providers to assume stigma and choice inhibit uptake by Irish people, without questioning the accessibility or acceptability of mainstream services.

# A PROFILE OF OLDER IRISH PEOPLE IN BRITAIN

The age profile of the Irish population in Britain and a myriad social and health factors increase the risk of dementia and age related mental health problems.<sup>1</sup> This article focuses on migration, socio-economic and health status and distinctive cultural factors relating to dementia risk. The Irish comprise 0.9% of the population in England and Wales, varying from 2.2% in London to 0.2% in the North East. Large concentrations exist in metropolitan and former industrial cities and a significant proportion live in areas ranking high on indices of multiple deprivation (Tilki et al 2009).

The age profile of the Irish community is distinctive with a higher proportion above 50 and particularly beyond pension age than in general or minority ethnic populations. Most BME elders are among the 'young-old' whereas the Irish are disproportionately represented in the 'old-old'

category (Shah 2007). Consequently, there is a high level of informal care within the Irish community (Tilki et al 2009). Older people are largely concentrated within high Irish populations, but areas with small Irish communities frequently have sizeable percentages of Irish elders. Population density has implications for health and social support (Karlsen & Nazroo 2002). Therefore elders who live in areas with fewer Irish people may be more isolated and marginalised than their peers in traditionally 'Irish' settlements.

As in older groups, many older Irish people are widowed, with some separated or divorced. Because of their occupational history, Irish people over 50, and especially men are more likely to have remained unmarried than British and other populations and are therefore more likely to live alone, without partners or children to support them when they become frail. They are also less likely to be in contact with Ireland due to death of parents and increasing frailty among siblings who might have offered support by visits, letters or telephone.

Although many Irish people worked in top occupational groups, the majority of older people were employed in elementary occupations, often without provision for national insurance or pensions. Lower wages and few if any social insurance contributions account for lower pensions (Tilki 2003) and explain the considerable socioeconomic disadvantage experienced in later life (Evandrou 2000). Although the age profile means significant numbers of the Irish population are retired, it is important to note that economic inactivity due to poor health is particularly high among men between 50 and 65 (Tilki et al 2009). Apart from the impact on income, economic inactivity generally leads to isolation ,causing depression and exacerbating the ill-health which caused premature exit from work.

There is robust evidence of high levels of self-reported poor health, limiting long term illness and disability especially for those aged 50 and over (Tilki et al 2009). Irish people have dispro-

<sup>&</sup>lt;sup>1</sup> The scope of this article is limited but a full account (Tilki et al 2009) is accessible at http://eprints.mdx.ac.uk/6350

portionately high rates of cancer, heart disease, hypertension and stroke, particularly in older age bands (Harding et al 2008; Wild et al 2007). The incidence of mental illness is high, with excessive rates of depression, anxiety, psychological illhealth (Ryan et al 2006; Sproston & Nazroo 2002; Weich & Mc Manus 2002), suicide and attempted suicide (dePonte 2005; Neeleman et al 1997). In-patient admission rates among Irish people over 50 are higher than in the general population (CHAI 2007, 2008). The Count Me In Census of 2009 demonstrated that Irish people above 65 were disproportionately represented in admission figures (CQC 2010).

# THE IRISH MIGRATORY EXPERIENCE

Tilki (2003) and Leavey et al (2004) describe complex factors associated with migration and highlight distinctive, gendered migratory patterns for Irish people compared to other migrant groups. Migration from Ireland generally involved single people rather than families and women often migrated alone. The proximity of Britain meant that emigration was largely unplanned without expectations of settling. While poverty and unemployment are cited as the main reasons for leaving Ireland, evidence of a desire to escape a claustrophobic, oppressive and unfair society is widespread (Leavey et al 2004; Tilki 2003). In addition to economic factors, a significant proportion of Irish men and women migrated to escape abuse in institutions or the family (Raftery & O'Sullivan 1999). Their migration was unplanned and they carried a range of physical and mental health problems (Ryan et al 2006), which were compounded by the difficulties they faced in Britain (McGee et al 2008).

Arriving in England afforded freedom and companionship for many, but was coupled with displacement, insecurity, loneliness and homesickness. While many found the English polite and respectful, they invariably felt like outsiders with little in common with the host society. Anti-Irish sentiment in Britain has been expressed differently across the decades, ranging from simian representa-

tions of the stupid 'Paddy' in the early 20th century (Curtis 1984) to parliamentary discourses about the drunken, criminal and dirty Irish in the 1950s and 1960s (Hickman 1998). Although Irish people worked in farms and factories alongside the English during World War II, they were seen as a threat to national security and were taunted about Ireland's neutrality. However the 'troubles' in Northern Ireland from the late 1960s legitimated the most public expressions of anti-Irish racism and draconian police powers though the Prevention of Terrorism Act 1974 (Hickman & Walter 1997). While anti-Irish sentiment has arguably disappeared in recent years, the experiences of the past have taken their toll on mental health and are still very vivid for the older generation.

#### **DEMENTIA RISK**

The risk of dementia is reflected in the older age profile of the Irish community and in particular the proportion of those in the very oldest category where dementia is more prevalent. Although dementia in visible minority groups is increasing, evidence from Irish community organisations highlights a high incidence already (FIS 2010; Mulligan 2007). There is a need for further research, but existing evidence linking social isolation and depression (Cattan et al 2005) and depression and dementia (Ritchie et al 2010) resonates with the situation of older Irish people in Britain.

The high incidence of people living alone through widowhood, divorce or never having married predisposes the older Irish population to social isolation. Ill-health, unreliable transport, low income and the fear of going out in deprived areas exacerbates this risk. Social isolation contributes to depression, which increases the risk of dementia (Ritchie et al 2010). Isolation itself contributes to depression and/or dementia and there is nobody to notice withdrawal, cognitive impairment or neglect. Isolation limits the availability of information, resources and services and there is nobody to confide in or encourage the person to seek help. Embarrassment about poor memory, language problems, or altered behaviour

makes people with dementia and their carers reluctant to leave home. Past experiences of racism, insensitivity and hostility compound their reluctance to seek help. Thus diagnosis, access to treatment or opportunities for helpful voluntary and statutory support is delayed.

The risk of dementia among older Irish people may be greater because of the high incidence of poor psychological health and common mental disorders such as depression and anxiety (O'Connor & Nazroo 2002; Sproston & Nazroo 2002). Multiple factors contributing to mental ill-health among Irish people make it difficult to prevent, but reducing social isolation may help in preventing depression and accessing early help might reduce the risk or delay the onset of dementia. Equally, addressing barriers which prevent Irish people from accessing services could reduce social isolation and increase the chances of preventing or delaying problems or of obtaining support and treatment which could improve quality of life.

Evidence shows that older Irish people are particularly reluctant to use mainstream services and when they do are often dissatisfied with them (FIS 2010; Tilki 2003). Irish people repeatedly complain that regardless of the illness, health professionals stereotype and presume alcohol is the problem:

The first question, the very first question is always, how much do you drink?. I don't drink alcohol at all but you get a sense they don't believe you. (Bridget – service user)

Staff have difficulty with Irish accents, make few attempts to understand, instead ignoring or making fun of service users. Although Irish people speak English, the way English is spoken may be misunderstood.

I have to keep repeating myself. Nobody understands my accent. (Tom – service user with memory problems)

The following example illustrates how older Irish people often use a negative construction when asking for help. The word 'bring' rather than 'fetch' is also widely used.

Maura, a client at the local day centre was feeling chilly. She approached two different members of staff 'you wouldn't be a great help and bring me my cardigan would you?' The first person ignored her and later admitted she hadn't understood what the client wanted. The second person laughed and repeated it to the others in the room, making teasing remarks which Maura found offensive. (Outreach worker, South London)

Irish people accessing mainstream social or therapeutic activities find no account taken of the specific migration experience of Irish people or the discrimination faced over many decades.

Oh yeah, so we sing 'Roll out the Barrel'. Sure, we worked side by side in the factories, but they made it very clear that it wasn't our war. They jibed us constantly – 'Ireland sat on the fence, Ireland stayed neutral'. (Vera – service user, London)

Nobody was ever rude or said anything to your face, but it's hard to forget the 'No Blacks, No Dogs, No Irish' signs. (Eamonn – service user, Manchester)

Evidence demonstrates that social integration and social activities reduce the risk of depression (Fratiglioni et al 2004; Cattan et al 2005) and help in preventing dementia (Ritchie et al 2010). There is therefore much to gain from addressing the cycle of social isolation in which Irish people can become entrenched. Making services culturally sensitive to Irish people cannot reduce the risk of dementia, but breaking down barriers can encourage them to access facilities which improve the quality of life for those with dementia and their carers.

# THE EMERGENCE AND EXPANSION OF THE IRISH VOLUNTARY (THIRD) SECTOR

Anti-Irish racism led to the emergence of voluntary Irish community organisations as points of

contact and social interaction in areas of high Irish population from the 1970s onwards. Later, in response to dissatisfaction and discomfort with insensitive racist mainstream services, community organisations began to provide information, advice, care and support and housing services for the Irish in Britain (Tilki 2003). Recent mapping undertaken by the Federation of Irish Societies (FIS 2010) shows at least 52 organisations providing specialised services for elderly people and ten more offering facilities not specifically for elders but accessed by them. The range is extensive, from sophisticated welfare provision outreaching vulnerable people and supported housing to selfhelp pensioner groups, lunch clubs and social groups. Many of these services are either funded by the Irish government or developed through grants from Ireland as reciprocity for migrant remittances, which supported the Irish economy before the Celtic Tiger. There is therefore wide variation in how organisations engage with Primary Care Trusts, Local Authorities or strategic partnerships. Larger groups are commissioned to provide elders with mental health services, health promotion campaigns, information or advice services, or venues for chiropody, health checks, or various primary care services. Many small groups operate 'below-the-radar', run by volunteers, funded by raffles, benefit dances, donations, membership fees or charges for activities. Most organisations involve a combination of both with an army of volunteers, some professional staff and variety of precarious funding sources.

# CULTURAL SENSITIVITY AND SERVICES FOR OLDER IRISH PEOPLE

Much is made of the importance of welcome in the Irish community, symbolised by the traditional *céad míle fáilte* or 'hundred thousand welcomes'. Clearly a genuine welcome can be offered by non-Irish people, but for vulnerable elders and those with dementia, workers need to be able to understand Irish accents, the way English is spoken, pronounce Irish names and respect the culture and heterogeneity of Irish people. It is particularly important to appreciate the experiences of Irish people and be au fait with sensitivities around institutional abuse, alcohol misuse, religion and the impact of stereotypes. It is critical that a worker or volunteer can communicate in Irish (Gaeilge) with native Irish speakers who have lost their ability to speak English after many years of speaking it.

Reaching out to the Irish community has practical and psychological elements. Poor health, poverty and lack of transport prevent participation, so several initiatives provide transport to and from lunch clubs. Although Irish people are reluctant to use mainstream services, a number are also unwilling to approach Irish services unless tried and recommended by a trusted party. Therefore several organisations outreach to marginalised people using culturally sensitive staff and trained volunteers. There is undeniable stigma around mental illness, but Irish organisations focus on being welcoming, non-judgmental and non-stigmatising. They value confidentiality but encourage people to talk about difficulties and share experiences in a safe environment, while helping them recognise the structural roots of problems, rather than blaming themselves. In particular, they operate a strengths model, recognising problems, but focussing on and capturing the strengths and resilience of the individuals involved.

While images of shamrocks, leprechauns, and crocks of gold reek of 'paddywhackery', such traditional imagery may be very meaningful and comforting to vulnerable people or those with dementia. Posters, photographs, county coats of arms, Irish background music and familiar accents help people feel safe and at home.

I enjoyed the local clubs but Paddy was restless, withdrawn and unhappy. The only place he relaxed was at the Irish lunch club. He could have a laugh and a joke. ... As his condition deteriorated and his speech was muddled, his face would light up when he heard the accents. He was with his own people. (Rita – carer, London)

An active and socially integrated lifestyle can protect against dementia in later life (Fratglioni et al 2004). Therefore Irish organisations perform a significant role in enhancing social support networks (Cant & Taket 2005), introducing people to each other and encouraging contact outside group events. The function of lunch or social clubs goes beyond food or social activity. Getting out of the house once or twice a week is stimulating for people with dementia as well as offering a brief respite to the carer.

For me it's a 100% good. The week seems to go faster. I love coming and I don't know what I would do without it. (Pat – service user with memory problems)

Stimulation and social interaction with other (mainly) Irish people are facilitated through music, exercise, bingo, card games and more.

I look forward to coming and recounting the old times with the group. I enjoy the memory loss sessions each Thursday, meeting with friends all suffering from memory loss. (Michael – service user with memory problems)

Speakers give practical information about matters relevant to older people such as home and fire safety, health and general wellbeing. The 'surveillance' element of lunch clubs is non-intrusive but invaluable as workers and peers watch out for somebody who hasn't attended or who appears to be in need of help. Staff or volunteers are well placed to raise awareness of dementia issues, linking people with dementia and carers with relevant statutory services according to need.

Irish organisations invariably provide Irish newspapers, films and DVDs and variously incorporate them into discussions which stimulate verbal abilities, promote conversation and enable people to keep up to date with current events. Requiem masses, wakes, funerals and memorial services are an important part of Irish culture which celebrate the lives of and demonstrate respect for deceased members of the community.

Rather than being morbid or reminding people of their own mortality, they are reassuring and comforting especially for those without family.

Research evidence shows that physical activity in midlife can reduce the risk and/or delay the onset of dementia in later life (Rovio et al 2005) and a number of Irish organisations provide exercise sessions for people of differing physical abilities. 'Tea Dances' are highly popular afternoon events offering social interaction, exercise and continuity as people maintain the traditions of their youth and young adulthood. While some may be too frail to engage in physically demanding 'sets' or *céilis*, many are able to enjoy a gentle waltz. This provides not only physical exercise but affords opportunities for reminiscence and social interaction.

Mapping undertaken by the Federation of Irish Societies (FIS 2010) shows a number of services specifically provided for Irish people with dementia and their carers. These initiatives fit comfortably alongside the National Dementia Strategy (NDS) and address some of the wider failures of the strategy (APPG 2010). The aims of Irish dementia services mirror those of the NDS (DH 2009) particularly in improving community awareness, accessing early diagnosis and intervention, and providing quality information for people with dementia and their carers. Community organisations offer a range of culturally sensitive reminiscence and therapeutic activities, respite for carers, peer support and advocacy around home or residential care. They are increasingly asked to provide culturally sensitive services for older Irish people in residential care, presumably in response to the All Party Parliamentary Group report (APPG 2009) on the skills gap in dementia care.

Irish music is a major focus of the activities in Irish community organisations for all participants but plays a key role in expressing emotions by people with dementia. Memory for familiar music is particularly well preserved even in advanced stages of dementia (Cuddy & Duffin 2005). Background music can calm agitation,

aggression and increase sensory awareness and communication (Wall & Duffy 2010). Music can be taped or live but singing is particularly valuable in dementia (Gotell et al 2003). Experience within Irish organisations suggests that singing helps with language and people with dementia find great joy in interacting with others and remembering the songs they sang as children.

While there are questions about the underpinning research base, there is evidence that reminiscence contributes to mental health (Westerhof et al 2010) and can be valuable in dementia care (Moos & Bjorn 2006). Reminiscence involves sharing autobiographical memories and is undertaken by staff who are culturally competent with facilitation skills. This means understanding the Irish migratory experience, anticipating and being sensitive to grief, pain and loss often buried for decades. Facilitators are adept in handling sadness at leaving home, bereavement, discrimination in Ireland and Britain, perceptions of failure, not being able to return home and ending their days in another country. Abuses experienced in institutions or the family emerge in reminiscence from time to time but require more specialist help than reminiscence can offer.

# SERVICES FOR CARERS, RESPITE AND ADVOCACY

There is a high level of informal care within the Irish community, with a significant proportion of carers providing 50 or more hours care per week (Tilki et al 2009). Many do not consider themselves carers and see this as part of their role as wives, husbands or daughters (Tilki et al 2009). As with others caring for people with dementia, many carers are old, frail and in poor health. Most have little knowledge about services but some fear that if they ask for help, the person they care for will be placed in residential care. In addition to the lunch clubs, which offer a brief episode of respite for carers, a number of Irish organisations provide specific facilities to give carers a break which the statutory sector fails to provide.

Pat [husband] seems to have had a good day today. He said he had been to school. He enjoys Thursdays – his face lights up when he sees the bus coming to collect him. It is the only time I have to myself. I go swimming and shopping without worrying and that means a lot. (Anne – carer, London)

One organisation facilitates a carers' support group, which encourages carers to socialise, share problems and support each other. It provides information about dealing with the person with dementia, avoiding back and other injuries and how to handle the abuse that carers often experience. Outings are organised and carers are encouraged to contribute their experiences to local conferences and consultations. A 'Carers Cafe' initiative in another venue allows carers and cared for to socialise in an informal environment. It is run by volunteers who have received dementia training and includes reminiscence sessions which are very popular with those who attend.

Given the very limited provision for respite care by local authorities, one particularly innovative and highly valued initiative is a sitting in service for carers. Trained Criminal Records Bureau (CRB) checked volunteers get to know the person with dementia and the carer over a period of time until the carer is confident enough to have a break for a few hours.

A significant part of the work of Irish organisations is providing information about benefits and services and especially about dementia diagnosis, treatment and management. Advice workers or social workers assist families applying for allowances or more commonly appealing decisions about benefits or care services. Organisations provide advocacy around care services, home adaptations, respite care or related matters. However Irish families frequently have an additional barrier to overcome – recognition of the cultural needs of the person with dementia. The following casework undertaken by a London organisation highlights the obstacles and discrimination which can be faced by Irish families:

A daughter caring for her elderly parents requested assessment to see what care package was needed. During the interview she asked if there was any possibility that the care workers could be Irish, as her parents would be 'more comfortable with their own people'. She was told that they could not provide Irish carers. The care package started and there were problems with some of the care workers. The daughter complained time and again. She was told she was racist as she only reported black workers. She felt very hurt and contacted our project and I worked with her to write a formal complaint to the local council who had commissioned the service.

The matter was finally resolved and her complaints were upheld. She received an apology from the care agency regarding being accused of racism. The care agency admitted her initial request for Irish care workers had 'singled her out as a racist' as she was asking for white carers. This was not the case. We pointed out that all the care workers were black, but only some had been reported. They did not see Irish people as an ethnic group, but part of the white British population.. (Carer's Support Coordinator, London)

Sadly, this case study is far from unique and although services for other ethnic communities are not satisfactory, there is at least recognition that they have specific cultural needs.

# BIG COMMUNITY, BIG SOCIETY?

Despite the positive examples shown there is considerable unmet need in relation to older Irish people but particularly those with dementia and their carers. The Irish community in Britain has taken responsibility for addressing myriad problems over several decades but in doing so, has remained under the policy radar. Without grants from the Irish government, larger Irish third sector organisations in Britain could not have developed and smaller 'voluntary' groups would not have survived. This is a lesson for the Conserva-

tive Liberal Democrat coalition government's Big Society agenda (Cabinet Office 2010).

There is real concern that the Big Society agenda is more to do with cutting cost than empowering communities. It is unclear how much will be invested, where the money will come from and how fairly it will be allocated. Additionally, although the delivery of the NDS to date inspires no confidence (APPG 2010), there is great anxiety that the strategy will not be prioritised or even adopted by the coalition government. Given the past neglect of the Irish community and the urgent need for dementia services there is real concern in the community.

Notwithstanding these concerns, an army of Irish volunteers already exists supporting people with dementia and their carers. There is further scope to recruit from retired Irish health/social professionals, capturing their skills and cultural sensitivity. Retraining Irish people who are economically inactive for health reasons would be highly effective for all concerned. However without coordination, provision will be fragmented, haphazard and ineffective. Resources are needed to ensure that support is consistent, reliable and safe through training, supervision and checking of criminal records.

Preventing dementia and supporting home care is not a cheap option but it is significantly cheaper and more humane than institutional provision (APPG 2009). The Irish third sector already has a proven track record in delivering a range of professional services, replacing or supplementing public provision. There is considerable scope to expand these, but their survival, let alone their expansion, depends on sustainable funding which attracts and retains suitably qualified staff to provide services which meet the National Minimum Standards and the battery of legislation which must be adhered to.

David Cameron, the British Prime Minister has begun to refer to the third sector as the 'first' sector to underline its importance but his notion of the Big Society (Cabinet Office 2010) needs to be thought through thoroughly and impact assessed. The APPG (2009, 2010) recommendations for

the NDS and the current call for evidence to inform priorities for carers (DH 2010) are opportunities for different ways of addressing the needs of people with dementia and their carers. Within these frameworks alone, there is considerable capacity to develop the Irish third (first) sector to provide the help much needed by older people with dementia and their carers. While the authors argue strongly for culturally sensitive services for this section of the community, there is no reason why infrastructure and administrative functions could not be provided by partnerships with other Irish, BME, voluntary, statutory bodies. The foundations of the Big Society are alive and well in the Irish community in parts of England but they cannot progress let alone deliver without resources and support of government. It is highly probable that the experiences of the Irish in Britain are or will soon be echoed in other migrant communities in different parts of the world and that some lessons can be learned from the UK.

## References

- APPG (2010). A misspent opportunity?: Inquiry into the funding of the National Dementia Strategy. London: All Party Parliamentary Group on Dementia. Accessed August 10, 2010 at http://alzheimers.org.uk/site/scripts/download\_i nfo.php?downloadID=421
- APPG (2009). Prepared to care: Challenging the dementia skills gap. London: All Party Parliamentary Group on Dementia. Accessed August 11, 2010 at http://www.alzheimers.org.uk/site/scripts/download\_info.php?fileID=735
- Cabinet Office (2010). *Building the Big Society*. CAB 059-10. Accessed August 12, 2010 at http://www.cabinetoffice.gov.uk/media/407789/ building-big-society.pdf
- Cant, B. & Taket, A. (2005). Promoting social support and social networks among Irish pensioners in South London, UK. *Diversity in Health and Social Care*, 2, 263–270.
- Cattan, M., White, M., Bond, J., & Learmouth, A. (2005). Preventing social isolation and loneliness among older people: A systematic review of health promotion interventions. *Ageing and Society 25*(1), 41–67.
- CHAI (2007). *Count me in.* Results of the 2007 National census of inpatients in mental health

- and learning disability services in England and Wales. London: Commission for Healthcare Audit and Inspection
- CHAI (2008). *Count me in*. Results of the 2008
  National census of inpatients in mental health
  and learning disability services in England and
  Wales. London: Commission for Healthcare
  Audit and Inspection
- Coid, J., Kirkbride, J., Barker, D., Cowden, F., Stamps, R., Yang, M., & Jones, P. (2008). Raised incidence rates of all psychoses among migrant groups. *Archives General Psychiatry*, 65(11), 1250–1258.
- CQC (2010). *Count me in.* Results of the 2009 National census of inpatients in and patients on supervised community treatments in mental health and learning disability services in England and Wales. London: Care Quality Commission.
- Cuddy, L. & Duffin, J. (2005). Music, memory and Alzheimers disease: Is music recognition spared in dementia, and how can it be assessed. *Medical Hypotheses*, 64(2), 229–235.
- Curtis, L. (1996). Nothing but the same old story: The roots of anti-Irish racism. London: Information on Ireland.
- De Ponte, P. (2005). *Deaths from suicide and undetermined injury in London*. London: London Development Centre for Mental Health and London Health Observatory.
- DH (2009). Living well with dementia: A national dementia strategy. London: Department of Health.
- DH (2010). Refreshing the national carers strategy call for evidence. [Gateway reference number 14557]. London: Department of Health.
- Evandrou, M. (2000). Health statistic quarterly 08. National Statistics, Winter, 20–28.
- FIS (2010). Meeting the needs of Irish elders: Findings from the mapping of activities of Irish organisations in England and Wales. London: Federation of Irish Societies.
- Fratiglioni, L., Paillard-Borg, S., & Winblad, B. (2004). An active and socially integrated lifetstyle in late life might protect against dementia. *The Lancet Neurology, 3*(6), 343–353.
- Gotell, E., Brown, S., & Ekman, S. (2003). Influence of caregiver singing and background music on posture movement and sensory awareness in dementia care. *International Psychogeriatrics*, 15(4), 411-430.
- Harding, S., Rosato, M., & Teyhan, A. (2008).
  Trends for coronary heart disease and stroke mortality among migrants in England and Wales 1979–2003: Slow declines notable for some groups. *Heart*, 94(4), 463–470.

- Hickman, M. (1998). Reconstructing deconstructing 'race': British political discourses about the Irish in Britain. *Ethnic and Racial Studies*, 21(2), 289–307.
- Hickman, M. & Walter, B. (1997). Discrimination and the Irish community in Britain. London: Commission for Racial Equality.
- Husain, N., Chaudhry, N., Husain, M. I., & Waheed, W. (2009). Prevention of suicide in ethnic minorities in the UK. *Ethnicity and Inequalities in Health and Social Care*, 2(1), 10–17.
- Karlsen, S. & Nazroo, J. (2002). Agency and structure: The impact of ethnic identity and racism on the health of ethnic minority people. *Sociology of Health and Illness, 24*(1), 1–20.
- KCL/LSE (2007). *Dementia UK. The full report.* London: Alzheimer's Society/Kings College London and London School of Economics
- Kitwood, T. (1997). Dementia reconsidered: The person comes first. Buckingham: Open University Press.
- Leavey, J., Sembhi, S., & Livingston, G. (2004). Older Irish migrants living in London: Identity, loss and return. *Journal of Ethnic and Migration Studies*, 30(4), 763–779.
- Livingston, G., Leavey, G., Kitchen, G., Manela, M., Sembhi, S., & Katona, C. (2001). Mental health of migrant elders the Islington study. *British Journal of Psychiatry*, *179*, 361–366.
- McGee, P., Morris, M., Nugent, B., & Smyth, M. (2008). Irish mental health in Birmingham: What is appropriate and culturally competent primary care? Birmingham: University of Central Birmingham
- Moos, I. & Bjorn, A. (2006). Use of life story in the institutional care of people with dementia: A review of intervention studies. *Ageing and Society*, 26(3), 431–454.
- Mulligan, E. (2007). *Irish people with dementia in Leeds*. An internal report for Leeds Irish Health and Homes. Leeds: LIHH.
- Neeleman, J., Mak, V., & Wessely, S. (1997). Suicide by age, ethnic group, coroner's verdict and country of birth. *British Journal of Psychiatry*, 171, 463–467.
- O'Connor, W. & Nazroo, J. (eds) (2002). Ethnic minority psychiatric illness in the community (EMPIRIC) qualitative report. London: The Stationery Office.
- Oomen, G., Bashford, J., Shah, A. (2009). Ageing, ethnicity and psychiatric services. *Psychiatric Bulletin*, *33*, 30–34.

- PRIAE (2005). Black and minority ethnic elders in the UK: Health and social care research findings. Leeds: Policy Institute for Ageing and Ethnicity.
- Raftery, M. & O Sullivan, E. (1999). Suffer the little children: The inside story of Ireland's industrial schools. Dublin: New Island.
- RCP (2001). Psychiatric services for black and minority ethnic elders. CR103. London: Royal College of Psychiatrists
- RCP (2009). Psychiatric services for black and minority ethnic older people. CR156. London: Royal College of Psychiatrists.
- Ritchie, K., Carriere, I., Ritchie, C., Berr, C., Artero, S., & Ancelin, M-L. (2010). Designing prevention programmes to reduce the incidence of dementia: Prospective cohort study of modifiable risk factors. *British Medical Journal* 341: c3885. Accessed August 12, 2010 at http://www.bmj.com/cgi/content/full/341/aug05\_2/c3885
- Rovio, S., Kareholt, I., Helkala, E., Vitanen, M., Winblat, B., Tuomiehto, J., Soininen, H., Nissinen, A., & Kivipello, M. (2005). Leisuretime physical activity at midlife and the risk of dementia and Alzheimer's disease. *Lancet Neurology* 4(11), 705–711.
- Ryan, L., Leavey, G., Golden, A., Blizard, R., & King, M. (2006). Depression in Irish migrants living in London. A case control study. *British Journal of Psychiatry*, 188, 560–566.
- Shah, A. (2007). Demographic changes among ethnic minority elders in England and Wales. Implications for delivery of old age psychiatry services. *International Journal of Migration, Health and Social Care, 3,* 22–32.
- Shah, A. (2008). Estimating the absolute numbers of cases of dementia and depression in the black and minority ethnic elderly population in the UK. *International Journal of Migration, Health and Social Care, 4*, 4–15.
- Sproston, K. & Nazroo, J. (eds) (2002). Ethnic minority psychiatric illness in the community (EMPIRIC) quantitative report. London: The Stationery Office.
- Tilki, M., Ryan, L., D'Angelo, A., & Sales, R. (2009). The forgotten Irish: Report of a research project commissioned by Ireland Fund of Great Britain. London: Ireland Fund of Great Britain . Accessed August 12, 2010 at http://eprints.mdx.ac.uk/6350
- Tilki, M. (2003). A study of the health of the Irishborn people in London: The relevance of social

and socio-economic factors, health beliefs and behaviour. Unpublished PhD Thesis, Middlesex University.

Tilki, M. (2006). The social contexts of drinking among Irish men in London. *Drugs: Education, Prevention and Policy*, 13(3), 247–261.

Wall, M. & Duffy, A. (2010). The effects of music therapy for older people with dementia. *British Journal of Nursing*, 19(2), 108–113.

Weich, S. & Mc Manus, S. (2002). Common mental disorders in ethnic minority psychiatric illness in the community (EMPIRIC), in K. Sproston and

J. Nazroo (eds.) *Ethnic minority psychiatric illness in the community (EMPIRIC) – quantitative report.* London: The Stationery Office.

Westerhof, G., Bohlmeijer, E., & Webster, J. (2010). Reminiscence and mental health: A review of recent progress in theory, research and interventions. *Ageing and Society*, 30, 697–721.

Wild, S., Fischbacher, C., Brock, A., et al. (2007). Mortality from all causes and circulatory disease by country of birth in England and Wales 2001–2003. *Journal of Public Health*, 29(2), 191–198.

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