

Assembling Dementia Care: patient organisations and social research

Abstract:

In this paper, we take the concept of evidence-based activism as a point of departure to understand how Alzheimer's Disease associations have mobilized knowledge to re-articulate their role in the public sphere. We are specifically interested in political initiatives deployed by these organisations to shape the field of dementia care research, policy and practice in the last 5 years in the UK and Ireland. In both countries, the campaigns have emphasized the importance of developing and funding services and devices that mediate between the formal and the informal sectors of dementia care in order to support people living with dementia to stay at home for longer. Drawing on our analysis of documentary and interview data, our suggestion is that the transformation of dementia care into a 'matter of concern' is underpinned by Alzheimer's disease organizations' harnessing, fostering, sponsoring and circulating of social research conventions and methodologies such as the survey or the interview. Our main claim is that social scientific techniques and ways of reasoning have been key in the production and maintenance of boundary relations between informal and formal care in dementia. Our work can thus be seen as integrated in a renewed interest in understanding the epistemic cultures of social research and its relationship with political institutions of contemporary societies.

Keywords: Alzheimer's Disease; patient organizations; informal care; sociology of social research.

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Introduction

In the past four decades, health care policies in Western countries have emphasised the importance of prevention, health maintenance and self-management of illness as this is seen to lower mortality and morbidity, and foster choice and independence. This has been linked to an integrated approach to community care supported by new institutional arrangements between health and social care, ambulatory services and the use of health technologies at home. In the social care domain, the move toward the devolution of choice has combined with an increased recognition of the ‘mixed economy of care’, where public, voluntary, private and informal sectors are conceived as deploying increasingly complex relationships. In this context, voluntary organization have been proposed as key policy actors because of their expertise in providing specialist services, information and advice, and their unique knowledge of and role in supporting patients, informal carers and marginalized groups at the local level.

Research on this process has highlighted the paradoxical effects of such policies: while certain third sector organizations have financially thrived under such conditions, there is evidence that they are also becoming ‘stressed’ by the promotion of partnerships and alliances between providers, and by attempts to align their objectives through an emphasis on professionalization, evidence and effectiveness (Alcock, 2009; Lewis, 2005). Such paradoxes are, to a large extent, characteristic of neo-liberal or ‘governmentalised’ policy environments, as these rely on forms of knowledge mediated administration supported by the provision of information and advice to guide the conduct and choices of individuals and organisations (Lascoumes & Le Gales, 2007; Miller & Rose, 2008). The aim of our research is to understand how patient organisations themselves partake in the collective production of evidence to articulate their role in this knowledge mediated environment.

We focus on the field of dementia care, where the importance of developing and funding services and technologies that mediate between the formal and the informal sectors of care in order to support people living with dementia to stay at home for longer is consistently emphasised. We are specifically interested in campaigns and political initiatives deployed by Alzheimer’s Disease (AD) organisations in the United Kingdom and Ireland to shape national dementia strategies and the field of dementia care research, policy and practice in the last 5 years. In the UK, this has taken the form of the commissioning and propagation of a series of reports on the state and future of dementia care, coordinated by sustained public demonstrations and political lobbying (the 2007-2012 ‘Putting Care Right’ campaign). In Ireland, this has been mostly articulated in the *Dementia Manifesto* (2007 – 2009), a lobbying initiative based on a synthesis of survey data, health economic research and consultations with ‘stakeholders’. In both countries, the organisations have proposed a variety of

forms of support such as training standards for care workers, nurses and other community health and social care staff, support for carers in the form of home care, the promotion of dementia champions or advocates linking informal care networks to health and social services, and telecare and assistive technologies at home.

We take such political mobilizations around the *apparatus of care* as examples of evidence-based activism (EBA) (See Introduction to this special issue). In EBA, attempts to shape knowledge making practices and institutions are closely associated with interventions in the space of mobilization and the making of public issues. In this regard, knowledge is not simply a resource that patient and carer organisations mobilize; instead, organisations work to negotiate both the types of knowledge that are taken into account in collective decision making and how that knowledge is produced. This is particularly relevant in evidence-based policy environments where the boundaries of reliable, robust knowledge are constantly at stake (Moreira, 2012). EBA is thus characterized by patient and carers' organisations pragmatic emphasis on the *epistemic infrastructure* that sustains the very mobilization around specific issues, whereby patient and carer organisations' are engaged in the reflexive exploration of how to intertwine knowledge production and political process. In other words, EBA refers to how patient organisations' epistemic work contributes to the making and remaking of the conditions and patients around which they are mobilized and the contexts in which they seek to intervene. Drawing on our analysis of documentary and interview dataⁱ, our suggestion is that the transformation of dementia care into a 'matter of concern' (Latour, 2004) is underpinned by dementia organisations harnessing, fostering, sponsoring and circulating of social research categories, techniques and methodological devices such as the survey or the interview. In this, our research widens the scope of analysis in patient organization and health social movements' engagement with research which has until now, for the most part been confined to biomedical knowledge (Epstein, 2008).

In making this suggestion we do not want to suggest that social research is a stable collection of concepts and methods that can be mobilized for political purposes, as this would contradict the very notion of EBA that underpins our work. This is all the more important in the context of medicine and health care because social scientists have been active in questioning the theories of knowledge and related 'hierarchies of evidence' that are often associated with the evidence-based medicine movement (Pope, 2003; Mykhalovski and Weir, 2004; Broom and Adams, 2012). Indeed, our work can be seen as integrated in a renewed interest in understanding the shifting epistemic cultures of social research and their relationship with the social and political institutions of contemporary democracies (Camic, Gross, & Lamont, 2011; Law, 2004; Leahey, 2008; Osborne, Rose, & Savage, 2008). We seek to understand how and why patient and carer organisations engage with social scientific concepts and techniques in order to participate in evidence-based policy formulation.

While this epistemic investment is by no means unique to the field of dementia (see the articles on childbirth and rare disease activism in this issue), we propose that the AD organisations studied here emerged in and through the intertwining of social research and care policy between the 1970s and 1990. In the first section of the paper, we thus trace the processes by which social research came to be seen as an authoritative knowledge form to understand and manage the relationship between providers within the ‘mixed economy of care’. We describe how this process entailed a reexamination of the diminishing role of community and kingship bonds, and the encroaching power of the State in the narratives of modernization proposed by sociology and social policy, and how it generated controversy and uncertainty about the role of voluntary organisations in the articulation between informal and formal care (Bond, 1992a). Our suggestion is thus that AD organisations were constituted within a knowledge-laden process and that this helps explain their attachment to evidence-based forms of activism. Further changes in the disease and cause regimes of AD organisations in the 1990s (Beard, 2004; Moreira, 2009; O’Donovan, Moreira and Howlett, in press) strengthened their focus on shaping the forms of evidence and knowledge making procedures that equip care practices and institutions, a focus sustained through the mobilization of a diverse, hybrid set of social research techniques and concepts. As we describe in the main section of the paper, the use of this set of implements enabled AD organisations in the UK and Ireland to enact a ‘gap’ or mismatch between the perspectives and experiences of clients as ‘persons’ and the organization of formal dementia care services and, in turn, to reinforce their identity as ‘hybrid organizations’ mediating between informal, grassroots networks and formal organizations, linking across lay, professional, expert and policy forms of knowledge. Ultimately, harnessing social research enabled AD organisations to participate in policy formulation and to align their conceptualisation of the problem of dementia care with key health and social care policy networks.

Such analysis of the form of activism pursued by AD organisations should not be seen merely as an account of incorporation, and of pacification around the tensions we described above. In effect, much of the mobilization around the epistemic infrastructure of dementia care exactly concerned what AD organisations saw as the weaknesses and uncertainties surrounding the ability of social research techniques to capture the effect of care packages or technologies on the quality of life of the persons living with dementia (Moreira, 2010). In the main section of the paper, we describe further some of the elements of this critique of social scientific techniques and how it relates to the contention that the current epistemic infrastructure is not adequate to articulate the issue of dementia care. We also briefly explore how AD organisations have aligned with researchers to tentatively propose new methodological devices. In the concluding section, we suggest that this parallel exploration of political and epistemic dimension of dementia care has exposed areas of uncertainty in the form of activism advanced by AD organisations, which will require a more engaged role in designing

interview techniques and voicing devices for dementia research. These are new developments which fall outside our present research remit, but that should nevertheless be explored in further research.

Re-assembling care in Britain and Ireland

In this section, we are concerned with understanding the historical transformation of the co-productive relations between knowledge making and health and welfare institutions. We describe how, in the last four decades, Britain and Ireland converged towards an articulation of the composition of care that emphasizes the diversity and interdependence of providers. In Britain, this entailed a questioning of the dominant social policy ideals around the role of the State in the provision of welfare. In Ireland, the debate focused on negotiating the role of Catholic voluntary organizations in relation to the State and commercial providers of care. In both countries, however, social research played a key role in describing and making visible the differences and possible relations between forms of care.

Wither the Welfare State?

Historians, social and political scientists usually identify the 1970s as a period of transition with regards to the function of the State. Combined with the displacement of Keynesianism by neoliberalism as the dominant economic doctrine, transformations in the economic fabric of societies are seen as the context for emerging political questioning about the role of the State and the professions in the provision of welfare. This sustained debates in political circles and social policy thinking about whether further extension of State provision was necessary or a new approach to welfare was required.

In the UK, the publication of the Seebohm Report on Social Work in 1968 and the 1969 launch of the Community Development Projects programme mark the political recognition of the need to develop more responsive services and encourage ‘self-help’ or informal care, a process which eventually led to the funding and publication of what is usually recognized as a landmark document in the articulation of the idea of the mixed economy of care or ‘welfare pluralism’, the Wolfenden Report on Voluntary Organisations (Hadley & Hatch, 1981; Wolfenden, 1978). This presented a challenge to the orthodoxy of social policy theory, where a ‘shared vision of a more equal, more just society, with “better” social services financed through redistributive taxation’ (Wilding, 1983: 5) had been established since the 1950s. This challenge is however the result of a complex and somewhat incongruous relationship between political ideals, policy frameworks and social science’s conceptual and methodological innovations established a few decades before.

In the British context, this relationship was perhaps best embodied in the community studies approach (Bell & Newby, 1972; Young & Willmott, 1957), wherein the most significant example for our purposes are the studies led by Peter Townsend on the elderly. Located at the Institute of Community Studies, Townsend was part of network of social researchers who aimed to problematize the

sociological assumptions of the Welfare State, and in particular its disregard for the continuing role of primary relationships in post war Britain. Such questioning had been instigated, to a significant extent, by the collaboration between Michael Young and Edward Shils, who supervised Young while serving on a teaching post at the London School of Economics from 1952. Disputing some of the sociological founding fathers such as Tonnies, as well as his former Chicago colleague Louis Wirth and his collaborator Talcott Parsons's (1949) theories on the modern family, Shils had come to the view, based on the evidence collected by Young and Willmott that 'modern society [...] is no *Gesellschaft* [...] lacking any integrative forces other than interest and coercion [,instead] it is held together by an infinity of personal attachments and moral obligations' (Shils, 1957: 345; also Bulmer, 1996). Similarly, Townsend collected interviews with older people living in Bethnal Green to demonstrate that the extended family and its associated moral obligations had survived and transformed with the establishment of Welfare State. As a Fabian socialist, Townsend's aims was for the Welfare State to reform its atomistic assumptions about its citizen so as to understand older people 'as members of families' (Townsend, 1957: 227).

In this, Townsend saw the interview as a key methodological device because it avoided the perils of bureaucratization of social research, where the distance and objectivity of 'specialised techniques of questionnaire design, coding computing' created a chasm between the lived experience of the researcher and the subject (Townsend, 1957: 116). The techniques of the interview allowed him to render older people as knowledgeable, competent persons, managing a richly textured social environment, and to contrast this to the approach taken by social workers in assessing the needs of older people. This led to the claim, developed in subsequent studies, that usage of residential care and hospitals was significantly determined by the family structure of the older person rather than by his or her physical or psychological 'dependence'. Institutionalisation was, from the older people's point of view, a 'last refuge' (Townsend, 1962). Townsend's studies were of key importance in establishing social research's ability to make visible 'the independence and legitimacy of the client's point of view' (Abrams, 1978a: 96), and its capacity to gear health and social care programmes towards the realities and aspirations of older citizens (Victor, Scambler and Bond, 2008: 4-6).

This entailed a shift in social policy thinking, not only in reframing the role of primary relationships and 'informal care' in the planning of welfare, but also and crucially in the way social research was deployed to evaluate the effects of policy programmes (Offer, 1999). This is most visible, in this context, in the formulation of the 'production of welfare approach' (Davies & Knapp, 1981). Using a micro-economic analogy to understand the functioning of welfare, it drew explicitly on a vision of the relationship between experts and policy makers, where social policy analysts are no longer supposed to articulate principles of welfare but, instead, to take the 'implicit or explicit' policy objectives as 'reference points for gauging the degree of 'success' achieved by care' (Martin Knapp, 1981: 208). This relocation of social policy expertise to an empirical, technical role of assisting decision makers

shaped the role of social research techniques in the assembling of care services. The question became how to translate into measurement the dimensions of wellbeing and quality of life that were taken to be agreed aims of care programmes and initiatives, and a progressive questioning of the Fabian principles that had underpinned the discipline since the 1950s (Taylor Gooby, 1981; Page, 2010).

Such arrangement between social research and policy making became reinforced in the 1980s when a series of political initiatives in the UK attempted to firmly secure the role of informal care in the mixed economy of welfare, such as the 1981 White paper *Growing Older* or the 1988 Griffiths Report on community care (Graham, 1991a). Such initiatives proposed that professionals, private organisations and public services should assist rather than replace the ‘primary’ ties underpinning informal care. However, in this process, the question of the role of voluntary organisations remained open, as they were neither underpinned by ‘interest’, coercion nor personal relationships. Research and evidence collection on volunteering and the third sector became of key importance, so that from the beginning of the 1990s, a stream of research funding to understand the role of voluntary organisations in the provision of welfare emerged (e.g. Kendall & Knapp, 1996). From this perspective, social research was fundamental to what Kendall himself would later describe as a de-politicisation of the third sector role in care services and society more generally (Kendall & Taylor, 2009).

Negotiating corporatism

In Ireland, in the transition to the 1970s, policy negotiations revolved around the role of the Catholic Church in the provision of welfare within a ‘modern’ society, buoyed up by increasing prosperity and a reversal in the trend of mass emigration (Ó Cinnéide, 2010). Irish social policy thinking had strongly relied on the ideals of vocationalism and corporatism at least since the publication of the 1944 *Report of the Commission on Vocational Organisations*, which informed by Catholic social teaching, had extolled the merits of voluntary associations and the principle of subsidiarity (O’Leary, 2000). In this vocationalist model, the role of the State was minimal, but rather than leaving services to market forces they would be provided through the cooperative endeavours of voluntary associations. As a dominant political discourse in the 1950s, vocationalism was framed by a nationalist rhetoric, whereby the self-rule of the Irish was treated as analogous to the self-reliance of the individual, family and community, and where it was claimed that welfarist principles were a threat to the social fabric of Irish society (McDonnell and O’Donovan, 2009).

Indeed, the Catholic Church and Catholic associations had been significant providers of health and social care services since the middle of the nineteenth century and continued in this role up to recent decades. The residual nature of the Irish welfare state and its commitment to the principle of subsidiarity, which in the context of social care dictated that it should only be provided by the State as a last resort, was evident in the 1953 Public Health Act which made provision for funding voluntary

organisations to supply services ‘similar or ancillary to those provided by the Health Authority’. Voluntary organisations continued to receive special treatment by the State throughout the 1960s and 70s and to this day are the primary providers of ‘formal’ domiciliary care services for older people (Doyle and Timonen, 2008).

This focus on the family and community networks was supported by a continued interest in social research in the dynamics of tradition and modernity in Irish society since the classic 1930s study of ‘traditional’ family and community life conducted in Ireland (Arensberg and Kimball, 1940). This study created a blueprint both for the understanding of social relationships in Ireland and for the techniques used to depict it, so that subsequent community studies became concerned with the extent to which modernization and urbanization had eroded community and neighborhood relationships in Ireland (Brody, 1973, Curtin, 1988). This concern with decline of primary relationships was also present from the 1970s in survey research conducted by the Economic and Social Research Institute (ESRI) investigating the ‘modernisation’ of Irish families (Hannan and Katsiaouni, 1977). Established in 1959, ESRI was hitched to the state’s ‘modernization drive’ and became a major centre of policy-oriented social research with a strong ‘positivistic bias’ (Conway, 2006: 17-18). Then, the mid 1980s saw a boon to social policy research focused on management of the relationship between various ‘partners’ in the provision of social services, and a series of studies on ‘carers’ of the elderly in the home began to emerge. For example, in 1988 the government advisory body the National Council for the Aged published a two-part study *Caring for the Elderly* (O’Connor et al. 1988). This research emphasised that ‘family carers are the unrecognised backbone of community care—inadequately supported by State and other agencies in the task they have undertaken with such dedication and very often carrying out the task at great personal sacrifice’; it recommended a series of supports, including financial assistance, to ‘care for the carers’ (O’Connor et al. 1988: 3). Distinguishing between informal and formal caring, the key issue addressed by the study was how best to integrate the two categories of care, or the ‘balance between family and community help and state intervention’ (O’Connor et al. 1988: 44). Citing this research, the government policy *The Years Ahead – A Policy for the Elderly* (1988: 163) devoted a chapter to how a more constructive relationship could be promoted between ‘families, members of voluntary organisations and professionals working for statutory agencies’, the then three ‘major partners’ in the care of the elderly. By the early 2000s, funding programmes and academic centres focused specifically on ‘third sector’ research had emerged, such as the Royal Irish Academy’s Third Sector Research Programme.

The epistemic authority now conferred on social research articulated a dense web of relations between university social policy research centres, the State, and civil society organisations. Welfare policy was increasingly reliant on social research assessments of the state of family and community, and of the relationships between informal family carers and formal care workers, so that in questioning the underpinnings of Irish corporatism at the end of the 2000s, researchers were called to consider the

effectiveness of a move towards a 'quasi-market' and the introduction of 'cash-for-care' (Doyle and Timonen, 2008). Like in Britain, it was no longer the role of the policy analyst to consider the principles of care provision but to test the assumptions and processes of implementation of policies and programmes.

Alzheimer's Disease Organisations in context

The emergence of caring as both a political and epistemic problem identified relationships and forms of labour that were characterised as fragile yet fundamental to ageing societies. Mediated by the exchanges between policy and research explained in the section above, carers became engulfed in a network of shifting relationships that were seen to encompass local and national policy making, the shape and sustainability of services and, increasingly, the very structure of society itself. It is thus of no coincidence that the two organisations studied in this paper were established specifically as 'carers organisations' between 1979 and 1982 at the height of the British move towards welfare pluralism and the Irish consolidation of corporatism. Their establishment and evolution, however, tells also of the wider set of socio-technical relationships around Alzheimer's Disease and dementia. This is related to the reframing of the problem of senile dementia in terms of the biochemical, clinical and epidemiological features of Alzheimer's Disease in the 1970s. In this process, the US Alzheimer's Disease movement organisations had been fundamental to articulate a public concern, and give voice to a populations previously ignored by clinicians and researchers (Fox, 1989). Both in the UK and Ireland, individuals sought to emulate the success of the US AD organisations.

In 1979, the UK Alzheimer's Disease Society (ADS) was established with the aim of organising carer mutual support and providing information on the illness to members and the public. This was uniquely suited to the policy environment and, promptly in 1981, the ADS received its first grant from the Department of Health and Social Services (DHSS). This relationship with the DHSS was key to its development in terms of branches and membership, and to its establishment in the public sphere, so that by 1985 government grants accounted for 85% of the income of the organisation. The growth in income and expansion of the services provided by the ADS created organisational uncertainty (Plummer, 1996), which led to a 'major re-organisation'ⁱⁱ, and a focus on the provision of care services and a centralization of management in the following years. The profile and capacity of the organisation grew exponentially as result of these strategies and the functions of the society became increasingly interlinked. The focus on caring services saw the ADS fill a niche in service provision, supported by volunteers, who were in turn assisted by the information and advice provided by the Society. The expansion of the branch structure of the organisation was linked to its growing 'awareness raising' activities, which saw the disease become recognised in the public sphere and, in turn, fed into the growth of membership and branch formation. On the other hand, this focus on

service provision and the link with carers allowed the organisation to make its first steps into political lobbying' using the membership 'to produce political clout'ⁱⁱⁱ. Caring and '*caring knowledge*' became recognisably the public identity of the organization, claiming to have a 'unique understanding of caring issues, and knowledge based on patient experience'^{iv}. As a result, from the end of the 1980s, the ADS became involved in debates about the re-organisation of community care services, particularly through mobilisations around the need to quantify and understand the contribution of informal carers to the mixed economy of welfare.

Similarly, the Alzheimer Society of Ireland (ASI), founded in 1982, emerged at the beginning of a decade in which the long-standing commitment to the principle of subsidiarity in the Irish welfare regime was to find a new expression in social partnership. Initially, the primary cause around which the organisation mobilized was mutual support for carers, but through partnering with the State it was transformed into the country's main dementia-specific service provider and one of its largest professionalized patient organisations (Cahill, 2010). Alliances with State actors have not been confined to funding-for-services relationships, but were also established through awareness raising, political lobbying and partnership governance networks. The ASI successfully enlisted senior politicians to these activities; for example, the leaders of the four main political parties participated in publicity events for its first National Awareness Week, held in 1992, and the following year, this was launched by the country's president, Mary Robinson (*The Irish Times*, 8 July 1992, 8 July 1993). Since the early years of the organisation it has sought to influence public policy, evident in its submission to the government's Working Party on Services for the Elderly that published its report *The Years Ahead* in 1988, referred to in the previous section. Many of the ASI's early research activities were concerned with producing knowledge on the plight of carers of people diagnosed with AD. In the early 1990s, it commissioned researchers based in the Policy Research Centre in the National College of Industrial Relations to undertake a study entitled *Caring Without Limits? Sufferers of Dementia/Alzheimer's Disease – A Study of their Carers*. As noted in the preface to the report on this research, the study provided 'scientific' and 'statistical confirmation' of the ASI's experiential knowledge of the 'cost of caring' (Ruddle and O'Connor, 1993: iv). Nowadays the ASI asserts that its policy interventions are informed by 'a wealth of knowledge, expertise and experience', and in a new departure, including the perspectives of people with dementia (ASI, 2012: 5).

From the 1990s onwards, a series of epistemic, technological and political changes worked together to unsettle the relations between laboratories, clinics, carer organisations, regulatory and policy institutions that had established the bioclinical entity of AD two decades earlier. This involved a questioning of the boundaries between normal and pathological ageing, an increasing blurring between Alzheimer's Disease and other illnesses and the emergence of fractures within the space of representation for dementia (Moreira, May, & Bond, 2009). Through the increased public recognition

of dementia, fuelled by carer organisations, health and social care programmes came to integrate a variety of professionals and experts. This led to the generation of different accounts of the reality of AD and a critique of the medico-centric model of dementia (Bond, 1992b). One of most significant of these fractures resulted in the emergence of a coherent psychosocial model of dementia in the late 1980s developed by Tom Kitwood and others (Kitwood, 1993). This psychosocial approach generated models of person-centered care, and underpinned much of what Cohen (2006) quoting Leibling has labeled a ‘turn to personhood’ in the dementia field. The turn of the century was thus a period of transition for AD organizations, with attempts to integrate the perspective of persons living with dementia in the governance and shaping of activities (Beard, 2004; O’Donovan, Moreira and Howlett, inpress).

In Britain, further centralisation of management and standardization of service seemed to suggest that the ‘goodness of someone’s heart is not enough’^v, and, as the organisation aligned itself with ideals of personhood, internal debates emerged on who could best represent the needs of persons living with dementia. The now renamed Alzheimer’s Society’s (AS) response to these challenges was hybridisation, with the AS’ unique knowledge of AD and other dementias^{vi} assuming a mediating role between professionals, public services, scientists, carers and persons with dementia. This signaled a shift in the organization’s engagement with knowledge production and use, as the AS formulated its identity as actively and reflexively harnessing and shaping knowledge in tandem with the structuring of the organisation’s role in the public space. The organization thus works currently to define the epistemic infrastructure that sustains their capacity to shape the organization of dementia care. In this, the role of social research methodologies is of key importance.

In Ireland, the historical transformation of the ASI from being a carer to a carer and patient organisation was particularly challenging from both an epistemic and political point of view. From the early 1990s onwards, the organisation increasingly sought to encode and formalise the experiential knowledge of carers using the techniques of social research (Ruddle and O’Connor, 1993: iv). Aligning itself with the move towards personhood and identifying as a grassroots-led organisation uniquely positioned to mediate between people with dementia, their carers and the State, the ASI has had to intervene in efforts to develop social research techniques appropriate for use with people with dementia, rather than relying upon their carers as interlocutors or proxies. The strategy adopted to deal with this is similarly hybrid, as the character of the knowledge that it now produces and mobilizes is positioned as being doubly authoritative because it is both scientific and ‘grassroots-led’. This entails a dynamic interplay between the organisation’s drawing of social research techniques, its web of relations and its cause regime (who and what it is fighting for), all of which are involved in complex processes of co-production.

This epistemic and political repositioning of both organisations is evident in the evidence-based campaigns they both led in the mid to late 2000s. In the UK, the AS has focused its campaigning

resources on a consistent examination and public questioning of the state and future of dementia care, (the 2007-2012 'Putting Care Right' campaign). In Ireland, this has taken the form of a campaign around the *Dementia Manifesto* (2007 – 2009), which aimed to set standards for dementia care. In both countries, the campaigns drew heavily on social research techniques to emphasize the importance of developing and funding organisations and services that mediate between the formal and the informal sectors of dementia care in order to support people living with dementia to stay at home for longer. Below, we provide a detailed analysis of each of the campaigns.

'Putting care right'

The mid 2000s were difficult times for the AS, as it became entangled in a long public controversy with the National Institute of Health and Clinical Excellence (NICE) about access to dementia drugs on the NHS. Although seemingly disconnected from the question of carers, the controversy has revealed key divergences on methodologies to measure quality of life in dementia and the inclusion of carers' time in economic evaluations of therapies (Moreira, 2010). It was in this context that the AS commissioned the Personal Social Services Research Unit (LSE/Kent University) to produce a report on the prevalence and economic costs of dementia in the UK. Led by Martin Knapp, one of the originators in the 1970s of the 'production of welfare' approach referred above, the report focused on providing an evidence-based systemic diagnosis of dementia care to reveal the 'economic symbiosis' between the different providers of dementia care (Knapp et al., 2007: 84).

In this, the report can be seen as embodying the form of evidence-based activism favored by the AS. In the report, the issue of prevalence is seen as having key importance because it 'provides an authoritative and consistent foundation for health and social policy making, as well as assisting national Alzheimer's Associations in their task of raising awareness of the challenge to be faced by this and future generations' (Knapp et al, 2007: 8). For this interaction between knowledge, policy and politics to be accomplished, it was also crucial that the research team was able also to establish the prevalence of dementia in different care settings, and from that to estimate the current and future costs of dementia care. This calculation eventually revealed that over a third of costs of dementia care were incurred by family members, resulting in a 'saving' for public services but also 'loss' of income and tax revenue (Hunt in Knapp, Prince et al, 2007: xviii). This represented an alignment of the AS with the policy aim of maintaining people living with dementia at home for as long as possible, further reinforced by the identification, drawing on surveys and interview studies, of 'carer-related factors' as key reasons for institutionalisation of persons with 'complex medical conditions' in residential care. Carer support programmes such as home care packages should thus be combined with an increased reliance on dementia care training for community health care and primary health care providers. Such programmes also underpin the need to treat the person with dementia 'at all times with patience and respect for their dignity and personhood' (Knapp et al, 2007: 3). The report thus

advocates that the person-centered approaches to dementia care formulated by Kitwood and provided by the AS' training programme, should become a requirement for anyone involved in caring for persons with dementia.

The vision for dementia care proposed in the report served as the basis for a series of campaigns advanced by the AS in the following years: studies and mobilisations focusing on care homes (2007-08), hospitals (2009-10) and community settings (2011). Aiming to reinforce AS's role in shaping the health and social care agenda for people living with dementia, all three campaigns combine the use of in-house quantitative research with qualitative studies of patients and carers experiences and views typically presented in a 'hybrid format' (Moreira, 2012: 313).

The 2007 *Home from Home* report focused on the perceptions and experience of carers and persons living with dementia in different care settings. For this, the AS research team focused on gathering and classifying the perceptions of residents and in surveying the training and experience of staff and managers of care homes. For the first objective, standardised questionnaires were sent to the entire membership via the organisations' newsletter and filled by carers. For the second, the AS conducted a survey of staff and managers 'randomly selected from a database of all care homes' (Sharp, 2007: 43). Through the combination of a members survey and a 'randomly selected' care homes survey, the AS could build a picture of the issue of care homes that linked 'perceptions' and 'expectations' of informal carers with systemic issues to do with training and awareness. The combination of the two data sources made thus visible a 'gap' between the personalized needs of individuals living with dementia and the organizational culture of residential care, a gap for which training, evidence-based regulation, and the use of dementia champions should become the bridges to better care.

In 2009, the AS published *Counting the costs*, which focused on the experience of persons living with dementia in hospitals (Lakey, 2009). The methodology was similar to the one used in the *Home from Home* report, but there are also signs of a learning trajectory in the use and deployment of social research, particularly in the use of procedures of the academic peer review during its production. The report found that 'people with dementia over 65 years of age are currently using up to one quarter of hospital beds at any one time' (Lakey, 2009: xvi). Using survey data from four condition areas, the report went on to propose a series of interventions that would reduce the number of beds occupied by people living with dementia in hospitals, thus reducing the costs on the NHS as a whole. Again, it was the use of combined research tools to identify gaps between the needs of persons living with dementia and staff awareness that in turn enabled the AS to advance person-centred dementia care within the NHS.

In January 2011, the AS launched the final chapter of the 'Putting care right' campaign, focused on dementia care in the community. The *Support, Stay, Save* report argues that inadequate support in the community and in people's homes leads into people with dementia prematurely moving into care

homes (Quince, 2011). Following a similar methodology to the previous ones - a members questionnaire survey combined with a survey of a sample of half the registered home care agencies - the report found that there were inadequate levels of training in home care agencies and that professional carers found it difficult to engage with the person with dementia due to time or task pressures. Revisiting the sociological distinction between formal and informal care formulated in the 1970s (e.g. Abrams, 1978b), the report suggests that 'the amount of time home care workers spend with people with dementia should be based on whether it is sufficient to meet needs and aspirations, not on rigid time or task-based schedules' (Quince 2011: 5). However, rather than blame the home care services for this situation, the report locates the problem in the *epistemic infrastructure* of dementia care, that is to say, the 'continuing lack of evidence about the experiences of people with dementia in relation to home care and support at home more generally' (Quince, 2011: 6). This is of key importance to our argument.

Indeed, the representation of experience in the making of policy had been an enduring problem in the AS epistemic strategy, as its in-house research efforts were often seen to fall short of social science research standards. Thus, in 2007, as the outline for a national dementia 'plan' were being discussed, the AS contracted a piece of research that focused on the experiences of diagnosis and management of dementia to exactly address this knowledge gap. Commissioned to the Mental Health Foundation (MHF), a charity recognised by policy makers for its ability to use qualitative research techniques, the research drew on focus groups of people with dementia and carers to advise that the 'perspective' of people with dementia should be taken in consideration in shaping the services they use (Williamson, 2008). This was both a methodological and political challenge: how to take the perspectives of people living with dementia into account when usually assessments of effects of interventions/services are either clinically based or drawn from measurements of quality of life that use proxy-respondents (carers)? In effect, the AS itself was struggling with involving people living with dementia in the governance of its own organisation and services.

Thus, in a further report commissioned to the MHF, *My Name is not Dementia*, the views of people with dementia on their quality of life were to become the focus (Williamson, 2010). The project was encumbered by recruitment and methodological problems. It was not only that ethical requirements for research made it impossible 'to involve anyone who lacked the mental capacity to give their consent to participate' (Williamson, 2010): 14), but also specific techniques had to be deployed to gather the views of participants: picture cards representing domains of life/activity, and Talking Mats. Talking Mats is a communication package developed by the University of Stirling's Alternative and Augmentative Communication Research Unit.^{vii} It is structured according to 3 sets of picture symbols – topic, option and scale – which are arranged by users in a mat. Talking Mats are geared towards the elicitation of preferences within a predefined set of option which attempt to bridge communicative barriers between interviewers and interviewees. Drawing on these *voicing devices*, the research was

able to suggest that ‘people with dementia [...] do not automatically find their lives dominated by the condition itself’ (Williamson, 2010: 24). It called for the development of *hybrid* quality of life indicators that combine ‘objective’ with subjective domains of well-being (See Warner, Milne, & Peet, 2010). This represented the view that the *epistemic infrastructure* of current policy making was not adequate to articulate the issue of dementia care. Without new, better hybrid forms of collecting and making sense of the views of people with dementia, policy making would most likely exclude the needs of this population.

The Dementia Manifesto 2007 – 2009 and the campaign for a national dementia strategy

To set the context to understand the *Dementia Manifesto* of 2007, it is necessary to go back a few years in dementia policy making in Ireland. In 1999, the National Council on Aging and Older People published *An Action Plan for Dementia* compiled by health economist Eamon O’Shea and a colleague based in the Department of Economics in the National University of Ireland Galway. Evidence of the diffusion of ideas and ‘policy transfer’ between the UK and Ireland, the *Action Plan* had emphasised the importance of maintaining and developing what Kitwood (1997) called the ‘personhood’ of the individual living with dementia. Unlike the policy document published a decade previously, *The Years Ahead* (1988), and signalling the emergence of the private sector as a significant ‘partner’ in the mixed economy of care, the *Action Plan* was declared to be the outcome of consultations with ‘all major stakeholders’ including those in the statutory, voluntary and private sectors (O’Shea and O’Reilly, 1999: 11). The ASI was one of the key organisations consulted (using interviews and a seminar) in the process of drawing up the *Action Plan*. Relationships between statutory, voluntary and private sector organisations were identified as crucial to the implementation of the plan, where ‘more formal involvement in both the formulation and implementation of policy’ for voluntary organisations was recommended, along with measures to ‘release the considerable potential for complementary provision between the public and private sectors’ (O’Shea and O’Reilly, 1999: 26). Almost a decade later, however, much of the *Action Plan* remained unimplemented.

It was against this background that the ASI launched the *Dementia Manifesto 2007-2009* calling for dementia to be designated a national health priority. Consolidating the epistemic and policy networks between certain social researchers, the State and the patient organisation, the ASI commissioned Eamon O’Shea to produce the economic position paper *Implementing Policy for Dementia Care in Ireland: The Time for Action is Now* (2007) that was to present one of the three forms of evidence on which the *Manifesto* was based. This was a replication of the practice of the previous decade whereby the ASI commissioned the same academics who had been commissioned by the National Council for the Aged to produce research on the experiences of carers (Ruddle and O’Connor, 1993). Informed by ‘a comprehensive process of gathering information to identify the priority issues for people with

dementia and their carers', the *Dementia Manifesto* was the 'cornerstone of the Society's political lobbying campaign' (ASI, 2007). The three pronged information gathering process involved the convening of a National Consumer Summit, commissioning of the economic position paper, and consultation with the ASI's 'stakeholders'.

In June 2006, the inaugural National Consumer Summit took place in Dáil Éireann, the Irish parliament. Involving twenty people with dementia and their carers, this provided a deliberative forum at which the policies that impact on their lives and the changes necessary to better plan for and support them were discussed. Politicians were invited to the closing ceremony to mark this 'historic meeting' (ASI, 2006: 2). Describing a subsequent National Dementia Summit, the ASI CEO explained that its purpose was to provide a forum where 'we could listen, reflect and hear what those people were saying' (O'Connell, 2012). Furthermore, emphasising the role of the organisation as a bridge between patients and their carers and political actors, in the context of the ASI's participation in the preparation of the research review *Creating Excellence in Dementia Care* (discussed below), he went on to say:

Our aim over the last two years has been to make sure that the politics of dementia remains within government circles ... there is a need to continue to educate our political leaders in order that they may not forget who they are serving. (O'Connell, 2012)

Resembling the report commissioned simultaneously by the AS in the UK from Martin Knapp and his colleagues, the economic position paper *Implementing Policy for Dementia Care in Ireland*, published in February 2007, focused on prevalence and incidence rates of dementia and on the distribution of the 'burden of care'. This knowledge was mobilized to make 'the case for a significant public investment in dementia care as part of a new strategy of making dementia a national health priority' (O'Shea, 2007: 3). But it was also recognised that the research tools for such mobilisation needed further development, and that as a field of expertise 'the health economics of dementia is in its infancy' (O'Shea, 2007: 2). In the position paper, the limits of health economics and the tentative nature of the numbers produced are emphasised and explained with reference to the instability of data, methodologies and calculative devices. The provisional character of the estimated incidence rates, for example, and the epistemic infrastructure on which they hang, are recognised. When interviewed, O'Shea went further suggesting that at times health economists attempt to calculate the incalculable: 'I think that sometimes there's a spurious game played ... where economists are hired to do cost effectiveness studies when really you know it's not possible - I mean to put a value on this' (interview, Galway, 6 May 2011). While recognising methodological limitations, the position paper presented evidence of the heavy reliance on informal care in Ireland, where 57 per cent of the 'burden of care' was estimated to fall on family care, 33 per cent on residential care services, and only 6 per cent on community care.

The final evidential strand of the *Dementia Manifesto* was a consultation with the ASI's 'internal and external stakeholders', which relied on the social research technique of the survey. Two surveys were undertaken; participants in the first, totalling 45 people, were ASI board members, staff and volunteers, whereas the second was targeted at 'service users', 176 of whom responded. Consistent with the information circulated in the economic position paper about the distribution of the 'burden of care', in these surveys the 'overwhelming need identified relates to the development of community care services for people with dementia' (ASI, 2007).

In a 2011 issue of the ASI's newsletter *oASIs*, the CEO noted that it had been 'a tremendous year' for the organisation due to the announcement by the new government of its commitment in the Programme for Government for 2011-2016 to develop a National Dementia Strategy by 2013. Combined with other initiatives, the *Dementia Manifesto*, with its synthesis of diverse forms of knowledge generated using diverse methodologies, was deemed to have been effective in ensuring that 'the message from people with dementia and their carers is finally being heard'. This government announcement led to the establishment of the Dementia Advisory Committee, convened to advise on the compilation of an 'evidence-based research review' to guide the new Strategy (Cahill, O'Shea and Pierce, 2012: 11). Funded not by the State but by the philanthropic foundation Atlantic Philanthropies, the committee was co-chaired by Eamon O'Shea, and Suzanne Cahill, of the Living with Dementia Programme in the School of Social Work and Social Policy, Trinity College Dublin, and included representatives of the ASI together with an official from the Department of Health and other medical and social science academics. In a further fusion of different forms of knowledge, the research review published by this policy network – which focused on collating estimates of current and future prevalence rates and costs of dementia care, taking 'both formal and informal care into account', together with reviewing models of best practice – is to be 'complemented by direct consultation with individuals with dementia and their carers' (Cahill, O'Shea and Pierce, 2012: 3). A subsequent ASI (2012: 2) submission to the Department of Health on the National Dementia Strategy asserted that an essential element in development the strategy is recognition of people with dementia as 'experts in the lived experience of dementia' and of their significant role in dementia research.

Acknowledging that the National Dementia Strategy is being developed in 'the most testing financial circumstances', the authors of the research review eschewed the opportunity to comment directly on the implications of 'austerity measures' for care services. Adopting a pragmatic stance, they note that 'even within such binding budget constraints', there is scope to reconfigure dementia care in Ireland. To that end, they advocate the 'reallocation of some of the existing institutional resources' in order to develop community-based services (Cahill, O'Shea and Pierce, 2012: 132, 90). In a similar vein, at the conference at which the review was launched, the ASI CEO stated 'Resourcing ...isn't necessarily about money. It's about how we use our gifts and our talents and our ability to collaborate', suggesting that the assembling of dementia care remains the key policy challenge.

Weighty methodological challenges have arisen from this evidence-based activism. The historical transformation of the ASI from being a carer to a carer and patient organisation, prompted by a reimagining of the identity of the person with dementia, is of particular significance in this regard. Declaring itself as a grassroots-led organisation uniquely positioned to mediate between people with dementia and their carers and the State, the ASI has had to intervene in efforts to develop social research techniques appropriate for use with people with dementia, rather than relying upon their carers as interlocutors or proxies. The organisation has been confronted by this challenge in its research on telecare as a technology of ‘independent living’, where it has grappled with finding ways of communicating with people with dementia about the consequences of telecare for their quality of life (Delaney, 2010). That said, the ASI (2012: 5) claims that its submission concerning the National Dementia Strategy is unique because ‘it has the benefit of capturing the perspectives of people with dementia’. These perspectives were captured using a focus group with five patients in which the voicing device of ‘Cara Pairs’, one-to one-advocates, were employed to support the participation of the people with dementia. However, the challenges of consulting with people with dementia on policy issues is acknowledged and illustrated by the report on efforts to use the focus group to elicit experiences of diagnosis; it is noted that for some ‘the actual process of getting the diagnosis was now unclear or they were unable to recall it’ (ASI 2012: 43).

Social research and the assemblage of dementia care

In this paper, we argued that the campaigns organized by the British and Irish AD organisations around the social and technical *apparatus of care* can be seen as cases of evidence-based activism in that those campaigns required a parallel exploration of the political and the epistemic. As cases of EBA, they provide us with unique insight into the dynamic relationship between the processes of policy articulation and knowledge making procedures in health and social care.

Politically, AD organizations have drawn on the methodological devices and ways of reasoning of the social sciences to articulate their conceptualization of the problems of dementia care and assert their role in the mixed economy of care. In our case studies, the deployment of social research techniques enabled the representation of dementia care as a complex political assemblage, where achievement of the policy aim to maintain older people at home as long as possible depends on securing a service orientation towards personhood. The parallel use of different social research techniques enacted a gap between the perspectives and experiences of clients as ‘persons’ and the organization of services, a boundary that in turn challenged the ‘economic symbiosis’ of dementia care. Dementia organisations redefined themselves as hybrid, boundary organizations to bridge a gap that they themselves helped create and maintain. This leads us to the conclusion that social scientific techniques and ways of reasoning have been key in the production and maintenance of boundary relations between informal

and formal care in dementia. By drawing on the methodological pluralism of the social sciences and its established dichotomies – qualitative/quantitative, instrumental/affective, public/private, etc. – AD organisations reinforced their identity as ‘hybrid organizations’ mediating between informal care, ‘grassroots’ networks and formal organizational formats, and linking across lay, professional, expert and policy forms of knowledge.

It is important to note that, in these campaigns, the main dichotomy AD organization have borrowed from the social sciences is that between formal and informal care. Such distinction is far from being uncontroversial, as we mentioned above. Since the renewed policy interest in self-help and caring networks in the 1970s and 1980s, social scientists have debated the existence of this distinction and its wider economic and political function. For example, challenging the assumption of a well joined continuum between formal and informal care advocated by policy makers, Abrams proposed that formal care belonged to the ‘public world of bureaucrats’ while informal care related to the ‘private world of mothers’ (Abrams, 1978b: 2). Feminist social scientists suggested instead that such distinction partook itself in the division of labor within the political economy of care, where the unpaid labour of social reproduction was mostly ascribed to women (Finch and Groves, 1983; Graham, 1991b). It has also been argued that such distinction overstates the differences between forms of care, and fails to capture hybrid forms in intermediate zones between the public and private domains (Thomas 1993; O’Donovan, 1997). The politics of care proposed by AD organisations, however, as we have seen, advances a form of hybridity that relies heavily on the maintenance of a distinction that they see as needing to be bridged.

Epistemically, in wanting to represent and give legitimacy to the perspective of the person living with dementia in shaping the organization of services, AD organizations were faced with limitations in the methodological devices they were attempting to deploy. This was evident, for example, in the AS’ attempts to challenge the methodological underpinnings of quality of life measures, or in ASI’s own struggle on how to include the perspective of the person living with dementia in the evaluation of its telecare services. One possible interpretation of this tension is that the conceptualisation of dementia as an insidious, progressive disease that robs persons of their capacity to speak as individuals, a conceptualization that justifies the very ‘politics of anguish’ upon which the AD movement is based (Fox, 1989), clashes with the assumptions about the psychology of individuals that are embodied in the technique of the interview. As a confessional technique, the unstructured interview is intimately connected with the development of psychodynamic models of personality which view such ‘conversations with a purpose’ as a means to give coherence to experiences and emotions (Rose, 1985). As Savage (2008) argues, the transposition of these techniques to social research in the 1950s was embedded in a politics of subjectivity that viewed individuals as knowledgeable agents in their own social worlds. Such politics of method are clearly visible in Townsend’s own methodological reflections on the interview, discussed above. Such devices are adequate to translate the perspective of

carers as users and/or providers, but the ‘turn to personhood’ in the AD movement has required the exploration of methodological devices that can make visible the voice of the person living with dementia, such as Talking Mats and Cara Pairs. The difficulties encountered in renewing a politics of dementia around the ‘voice’ of the person living with that illness can thus be seen as intimately linked with the methodological instability of these new devices.

In this, we are not presenting a critique of existing social science instruments and devices as they are confronted by the methodological challenges of representing dementia. We see social research devices ‘as precious little institution[s geared] to represent [...] the social to all its participants, to perform it, to give it a form’ (Latour, 2005: 138). Indeed, if one key implication from this research can be articulated is that future changes in the politics of dementia care may ultimately depend upon whether patient and carers organisations and social scientists are prepared to collaborate in re-inventing social science methodologies and ways of reasoning to harness and represent the less than coherent world of dementia.

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ⁱ We conducted in-depth interviews with key actors (N=8) within the organisation focusing on the role of knowledge and evidence in the activities and governance of the organisation, guided by the case-study methodology applied in the overall project.

ⁱⁱ ADS Annual Report 1988: 5.

ⁱⁱⁱ ADS Annual report, 1988-89: 3.

^{iv} ADS Annual Report 1996-97: 7.

^v Interview with Eileen Winston, London, 11 October 2009.

^{vi} Harry Cayton in ADS Annual Report, 1996-97: 1

^{vii} See <http://www.talkingmats.com/>