

# **The impact of the National Health Service and Community Care Act (NHSCCA) 1990 on the ‘typologies of care’ of older people with functional dependencies living at home in Britain (1980-2001)**

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## **Abstract**

This research focused on the prevalence and incidence of the number of older people (65 years and older) reporting Activities of Daily Living (ADL) limitations and falling into various ‘typologies of care’ between 1980 and 2001 in Great Britain. A pooled, cross-section of six samples of older people (n=5513) reporting one or more functional limitations in the General Household Survey (GHS) Elderly Supplements in 1980, 1985, 1991, 1994, 1998 and 2001 were assigned into seven *typologies of care* based on the combination of reported help for ADL limitations: unmet need, kin independence, substitution, formal care specialisation; compensation; task specificity; and, supplementation/complementarity. British population estimates of these typologies are provided using published figures from ONS (England and Wales) and General Register Office for Scotland (Scotland). The impact of the 1990 National Health Service and Community Care Act (NHSCCA) on functional limitations and typologies of care is analysed and discussed. Findings show that there has been slight increase in the number of older people reporting functional limitations between 1980 and 2001. Receipt of informal care to meet functional limitations needs increased over the period of investigation to compensate for a sizeable decline in receipt of formal services, following implementation of the NHSCCA reforms.



This research has been funded by the ESRC Small Grants Scheme programme(RES-000-22-2261).

## **Introduction**

Demographic changes, notably increases in the size of the very old population, mean that the number of older Britons needing assistance with Activities of Daily Living (ADLs) will increase considerably in coming decades, even if optimistic assumptions about declines in rates of disability prove correct (Wittenberg *et al.*, 2006). Most of this help is provided by ‘informal unpaid’ caregivers, predominantly close relatives (Maher & Green, 2002). It is increasingly recognised as important that statutory authorities need to work with and support these caregivers (Young, Grundy & Kalogirou, 2005). A concomitant issue surrounding use of publicly provided formal services has been the impact it has on the provision of care by family and friends (informal care). There was concern on the part of policy-makers that past government initiatives (e.g., *National Health Service and Community Care Act 1990*) aimed at providing increased formally organised care to older people living in the community and supporting their carers, not only acted to supplement or complement care by family and friends but also served in some instances to replace it (Griffiths, 1998; DoH, 1989; 1998; OPSI, 1990). Fiscal pressures during the 1980s and 1990s also led local authorities to increasingly ‘target’ care services to those most in need; the result being that those older people with lower-level needs in terms of functional dependencies were not provided care services (Social Services Inspectorate, 1987, 1988). The emphasis of both policy directions has been to place greater responsibility on older people themselves and their informal support networks to provide care.

What we do not know, however, was the extent to which government fears about substitution of formal for informal care ever came to fruition, and more importantly, whether there has been a change in the balance of care provided by formal services and informal carers, as well as the relationship between the two in meeting the needs of functionally dependent older people in Britain. The research sought to gain greater understanding of *how* the relationship between formal and informal care for dependent older people living at home has changed in Britain by operationalising and testing competing explanatory models of the formal-informal care interface using a pooled cross-section data from a series of General Household Surveys (UK), combined with publicly available data from Health Authorities (HAs) and Social Services Departments (SSDs) between 1980 and 2001.

## **Research Design**

This research undertook secondary, univariate and multivariate analysis of pooled cross-sectional General Household Survey (GHS) data (1980, 1985, 1991, 1994, 1998, 2001) combined with publicly-available health and social services information and other relevant data to create a large cross-section, with time (GHS year) varying across sample units.

### **Data**

GHS data were restricted to those respondents aged 65 and over who responded to the Elderly People in Private Households supplement or 'trailers' survey in 1980 (n=4,516), 1985 (n=3,691), 1991/2 (n=3,785), 1994/5 (n=3,501), 1998 (n=3,082) and 2001 (n=3,356) and who reported at least one functional (ADL) limitation (Sample n=5513). Information for the latter was gathered using a combination of publications and data available from the DoH (e.g., Health and Personal Social Services Statistics for England, Wales, Scotland and Key Indicators Graphical System- KIGS) and ONS (e.g., Social Trends, Regional Trends), as well as relevant literature in the field of ageing and social policy (eg. Omnibus Surveys, Age Concern/Help the Aged surveys and reports).

### **Measurements**

#### **1) Personal Activities of Daily Living (PADL) and Instrumental Activities of Daily Living (IADL)**

Personal and domestic tasks common across each of the GHSs are presented in Table 1. There were fifteen ADLs (eight PADLs and seven IADLs) common across the six GHS surveys. From these common ADLs were created a number of binary variables, which distinguished two states: 1) no dependence at all on the part of the older person in performing the activity and, 2) some degree of dependence in carrying out the task. For PADLs, those unable to manage a task alone (or at all) were counted as dependent for that ADL. For IADLs, those who did not do a task and said that they would not be able to do so on their own (if they had to) were counted as dependent for that ADL. By combining PADLs and IADLs we were also able to show a mutually exclusive category of need: 1) PADL only, 2) IADL only, 3) Both PADL and IADL.

**TABLE 1  
PADLS AND IADLS COMMON IN GHS 1980, 1985, 1991/2, 1994/5,  
1998/9, AND 2001/2**

Primary activities of daily living (PADLs) <sup>i</sup>	Instrumental activities of daily living (IADLs) <sup>ii</sup>
1) Able to walk outside on own	1) Able to do household shopping on own
2) Able to get up and down stairs on own	2) Able to clean windows on own
3) Able to get around the house on own	3) Able to sweep floors/do vacuum on own
4) Able to use the toilet on own	4) Able to do laundry by hand on own
5) Able to get in/out of bed on own	5) Able to cook main meal on own
6) Able to wash/bath on own	6) Able to use fry pan/make snack on own
7) Able to wash face and hands on own	7) Able to make cup of tea on own
8) Able to feed self on own	

**2) Typologies of care**

Having knowledge of the major ADL domain (PADL versus IADL) and from which network the assistance was provided (i.e., neither, informal only, formal only, or both), allowed each older person’s care situation to be placed into a particular typology of care.<sup>iii</sup> 1) no help (Unmet Need); 2) informal care only (Kin Independence); 3) formal services only (Substitution); 4) informal care and formal services help received in some overlapping areas (Formal Care Specialisation); 5) informal care and formal services help received in some overlapping areas but in some areas which do not overlap (Compensation); 6) informal care and formal services help received but in different areas (Task specificity); and, 7) informal care and formal services help received in all the same areas of ADLs (Supplementation/Complementarity).

Table 2 presents an overview of seven major typologies of care. As the table shows, the major typologies are formed from specific combinations of type of ADL (PADL versus IADL) and by whom they are delivered (informal care or formal services). Determining each typology of care is simply a matter of going across cells and down columns for particular combinations. For example, if neither informal carers nor formal service providers help with any ADLs, then an individual would fall into the 'neither ADL' category for each source of care, resulting in the unmet need (no help) typology of care.

**TABLE 2**  
**MATRIX OF TYPOLOGIES OF CARE**

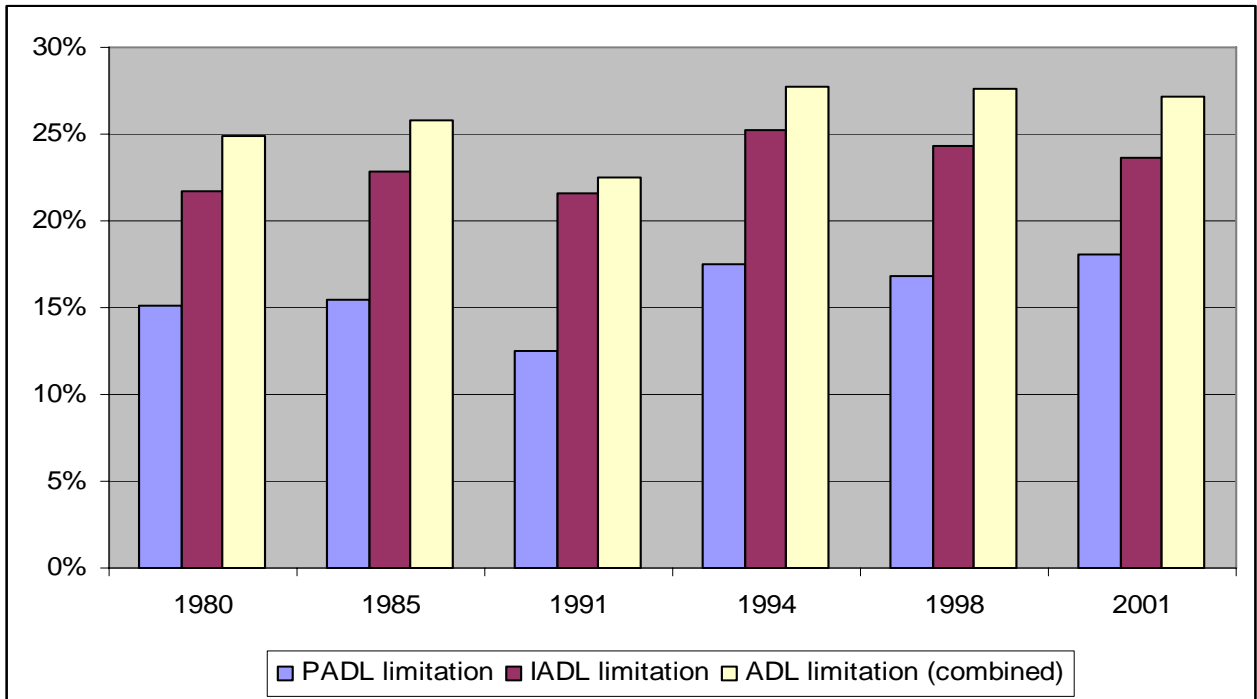
	<b>Formal services</b>			
<b>Informal care</b>	<b>Neither ADL</b>	<b>PADL help only</b>	<b>IADL help only</b>	<b>Both ADLs</b>
<b>Neither ADL</b>	Unmet need	Substitution	Substitution	Substitution
<b>PADL help only</b>	Kin independence	Supplementation/ Complementarity	Task specificity	Formal care specialisation
<b>IADL help only</b>	Kin independence	Task specificity	Supplementation/ Complementarity	Formal care specialisation
<b>Both ADLs</b>	Kin independence	Compensation	Compensation	Supplementation/ Complementarity

## **Findings**

### ***ADL limitations***

Figure 1 presents the proportion of older people reporting PADL, IADL and combined ADL limitations between 1980 and 2001. As the figure shows, the six GHS samples of older people also showed varying levels of personal care (PADL) limitations, with the highest number of older people reporting a PADL in 1994/5 and 1998/9 ( $\chi^2(5)=24.8$ ,  $p<.001$ ). Similarly, there were statistically significant differences in the number of older people reporting household tasks (IADLs) functional limitations ( $\chi^2(5)=52.9$ ,  $p<.001$ ). Taken together, older people in the latter samples were more likely to report an ADL limitation than those in the earlier samples ( $\chi^2(5)=37.7$ ,  $p<.001$ ).<sup>iv</sup>

**FIGURE 1**  
**PADL, IADL, AND COMBINED ADL LIMITATIONS, GREAT BRITAIN 1980 – 2001**

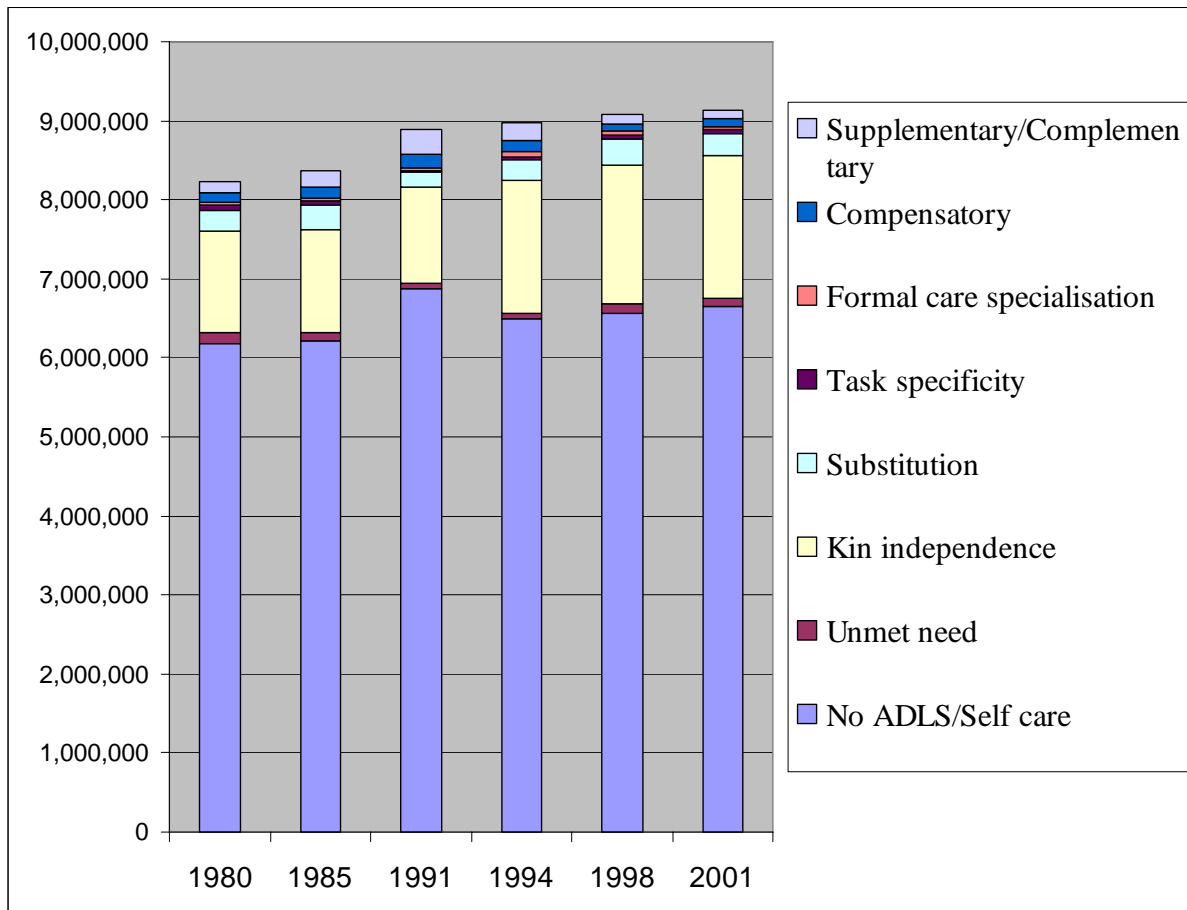


***Population estimates of typologies of care***

Figure 2 presents population estimates<sup>v</sup> the various typologies of care by GHS sample year. We have also included those older people who did not report any ADL limitations in order to show the full population of people aged 65 and older living in private accommodation in Great Britain. Results show unequivocally that the majority of older people across all GHS samples were not functionally dependent (in terms of ADLs) and are able to look after themselves on a daily basis and, where they were no longer able to; both informal and formal sources were called upon for assistance. But they also clearly show that the number of older people relying exclusively on their family and friends for help has increased over time, as has level of unmet need (albeit less dramatically), whereas the number of older people being supported by formal services alone (substitution) has decreased over time. So too has the use of both sources of care. We also find a general increase in the models in which there was provision by both informal carers and formal service providers between 1980 and 1991, after which there are decreases to levels – more often than not - below 1980’s in 2001. Taken together, the shortfall of older people receiving formal care services (alone or in conjunction with informal care) between 1994 and 2001 - estimated at roughly 170,000 older people -

has been compensated for by an estimated 134,000 more older people receiving care alone from family, friends and neighbours.

**FIGURE 2  
POPULATION ESTIMATES OF THE VARIOUS TYPOLOGIES OF CARE (INCLUDING NO REPORTED ADLS), GREAT BRITAIN 1980 – 2001**



**Specific sources of informal care/formal services**

By presenting estimates of changes in the use specific sources of care in the population, we are then able to suggest which contributed to the rise in informal care and decrease in formal care services over time. As the estimates in Table 3 show, the most support/help comes from spouse/partners living with older people. Results also indicate that number of older people receiving ADL related help from other household members has decreased substantially over time. However, the largest relative increase in provision of ADL related care over time has been from relatives living outside the household, which almost quadrupled between 1980 and 2001. Results also show that the level of support provided by friends/neighbours almost doubled in the period under investigation. A more pronounced impact in terms of the relationship between formal and informal care arose from estimates of utilisation of health and personal social services and paid help. Between 1980 and 2001 the number of older people using a health or social service provider for their ADL limitations decreased from just

over one-half million to just over 200,000. On the other hand, the number of older people paying for private help increased by more than 300,000. Taken together, the number of older people using health and social services went down by one-third, whereas those using private paid help to meet their ADL needs quadrupled.

**TABLE 3**  
**POPULATION ESTIMATES OF SPECIFIC SOURCES OF CARE, GREAT BRITAIN**  
**1980 – 2001**

<b>Sources of formal/informal care</b>	1980	1985	1991	1994	1998	2001
Spouse/partner helps	718, 693	721, 273	587, 633	895, 218	462, 136	862, 016
Other household member	712, 974	345, 265	872, 985	407, 850	712, 337	300, 571
Relative outside household	217, 324	591, 208	386, 919	990, 126	862, 458	856, 345
Friend/neighbour	183, 009	276, 685	350, 645	395, 024	206, 048	317, 585
Health/social services	529, 964	595, 937	502, 994	456, 587	270, 806	209, 833
Private/paid helper	114, 381	208, 105	282, 934	343, 723	400, 322	402, 652

## **Concluding Remarks**

There was very limited evidence supporting policy-makers' and government concerns about formal services substituting for informal care (*substitution* model), but there is evidence suggesting increased targeting of those most in need (*task specificity* model). Moreover, there was even greater evidence suggesting consistent and increasing care provided solely by informal caregiving networks (*kin independence* model) and paid private help over time (*formal care specialisation* model), with less and less support for older people and their carers from health and local authorities over time (*compensatory* and *supplementation/complementarity* models), as well as a slight increase in those not receiving any care or support for functional limitations (*unmet need* model). These trends in the prevalence and incidence of the various typologies of care took place firmly within the government's policy changes in community based long term care outlined in the introduction; namely that there was a great push by government to place the responsibility for supporting older people back onto informal support networks, but shows contradictory



evidence that it is working more closely with these carers to meet the needs of dependent older people. There is very strong evidence suggesting that the implementation of the National Health Service and Community Care Act 1990 has fundamentally altered the 'balance' between formal and informal care, resulting in typologies of care which disproportionately place the burden of care squarely on family, friends and neighbours of older people requiring assistance to live independently in the community, and financial burdens in terms of paying for care privately.

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Notes

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<sup>i</sup> The PADL Index was developed by Katz and colleagues (Katz, 1983; Katz & Akpom, 1976a; Katz & Akpom, 1976b; Katz, Ford, Moskowitz, Jackson & Jaffe, 1963). It is essentially a functional incapacity index, which measures one's ability to perform unaided six basic activities: 1) feeding; 2) continence; 3) transferring (to/from bed/chair); 4) going to the toilet; 5) dressing; and, 6) bathing/washing oneself. The distinctive feature of the ADL Index is that the items form a hierarchy in the order shown, so that those elderly people unable to feed themselves are usually also unable to manage any of the other tasks unaided; those who can feed themselves but who are incontinent are usually unable to manage any of tasks 3 to 6, and so on (Bone, 1995).

<sup>ii</sup> The originators of the IADL Index, Lawton & Brody (1969), specified eight instrumental activities: 1) using the telephone; 2) shopping; 3) food preparation; 4) housekeeping; 5) laundry; 6) travel; 7) responsibility for own medicine; and 8) ability to handle finances. They devised a scoring system to produce an index, but a natural hierarchy did not surface as it did in the case of the ADLs (although a hierarchical relationship between ADLs and IADLs is reported) (Spector, Katz, Murphy & Fulton, 1987). According to Bone (1995), IADLs are useful because they indicate less extreme forms of dependency than those covered by ADLs. Moreover, ability to manage one's personal affairs (i.e., handle finances) may be used to identify the presence of a dependent mental condition, like dementia, which cannot be identified by ADLs and IADLs alone.

<sup>iii</sup> Self-care (i.e., that care provided to oneself in the absence of any ADL limitations) was left out of the initial stages of the analyses because the main focus of this study is on receipt of informal care and formal services related to ADL limitation(s). It does, however, appear in the population estimates and projections section of the paper.

<sup>iv</sup> The variation showed in 1991/2 can be explained in part to changes made in the GHS survey for that year as well as the routing of ADL questions in 1991. In 1980, 1985, 1994, 1998 and 2001, older respondents were asked first if they could do a certain task on their own or if they needed help, or if they could not do it at all. If they answered that they could do the task, they were then asked a level of difficulty question, i.e., do you find it easy, fairly easy? In 1991, respondents were asked the second question as it appeared in the other survey years first and, only if they answered it was difficult or very difficult, were they asked if they could do a certain task on their own. Because the present analyses used only whether they could manage the task or not, we have made the assumption that valid harmonisation was affected minimally. However, results do appear to suggest that the question routing may

have affected the prevalence of ADLs for 1991/2 compared to the other GHS years. A decision was made to retain 1991/2 data as this was a pivotal year in assessing the implications of the NHSCCA.

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