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Unequal but equitable: an analysis of variations in old-age care in Sweden

Published online: 16 February 2006
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Abstract This study aimed to investigate whether contraction in services has led to inequitable service levels or simply large local variations. Previous attempts to explain service variations with aggregate, municipal level data have failed. We link representative Swedish data from 3,267 individuals aged 65 and older in 2002–2003 with coverage rates of public Home Help services in the 288 municipalities in which they reside. What past attempts have masked is that needs also vary substantially between municipalities; needs being defined as old people who live alone *and* need help with their activities of daily living (ADL). Once these local individual level variations are incorporated, municipal differences in public Home Help coverage largely vanish. Multivariate analyses confirm that advanced age, inability to perform ADL and solitary living are the major determinants of Home Help use. Variations in local supply have no association with individual use of public Home Help. These services are unequal but hence yet deemed to be reasonably equitable.

Keywords Home Help · Services · Needs · Equity · Regional variability

Introduction

Sweden and other Nordic countries have long prided themselves on their extensive system of home and community-based services (HCBS) for older adults and individuals with disabilities. At the core of these services, as directed by national mandate, are principles of equality and accessibility. These services saw rapid growth during the 1960s and 1970s, but have since contracted, relative to the more rapid growth in the older adult population. This contraction has led to a growing concern over what *equality* (i.e., uniformity) means, and whether the social welfare state still maintains HCBS in an *equitable* (i.e., responsive) fashion.

Historically, HCBS and institutional care have been a local (i.e., municipal, in Sweden *kommun*) responsibility in contrast to medical services which are controlled at the county council (*landsting*) level. Municipalities have considerable control over the nature and extent of HCBS they offer and as a result there is considerable variation in the extent of services available in specific municipalities. Some municipalities provide intensive services to a large proportion of residents while others provide services sparsely or less intensively. This observed lack of equality, in turn, has further fueled the debate over whether such services remain (or indeed have ever been) offered in an equitable fashion.

In order to better assess the extent to which services are truly being offered in an equitable fashion, however, it is necessary to consider the extent to which demand-side variables predict the availability of services, rather than simply how supply-side aspects of services interrelate as previous research has tended to do. To accomplish this, it is necessary to link micro-level individual data with macro-level municipal data.

Historical development of HCBS in Sweden

Before the secular *kommun* (municipality) was established about 150 years ago to administer poor-relief and

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other local affairs, this task was handled by the parish. Equity was not a high priority in the poor-relief era that ended in 1956, when institutional care was the only public service for old people, but authorities tried to at least achieve minimum standards in quantity and quality. Scandals in the public old-age homes forced the government to shift policy to promote HCBS over institutional care. In Sweden, government subsidies officially furthered this policy shift.

All municipal services are in principle financed locally, with municipal taxes (a flat rate at about 30% of income). Raising the taxes further is politically difficult, and therefore services for older people have stagnated and in most cases begun to shrink, over the past decade. In 2004, 7% of those aged 65 and older used institutional care and 9% used public Home Help, the major form of HCBS.

Services were free or charged nominal fees before the 1980s, but costs have since been raised with a ceiling to protect low-income elderly such that about one-third of them currently pay no fees. By and large, similar arrangements and challenges hold for the other Nordic countries, where also similar types of statistics are produced. Local variations are large in all the Nordic countries and indeed comparative studies of old-age care in these countries concluded that there were larger variations *inside* than between them (Daatland and Sundström 1985; Daatland 1997). Attempts to analyze these local variations have been undertaken in all the Nordic countries, but most energetically in Sweden (Berg et al. 1993; Trydegård and Thorslund 2001). They all failed to find any substantial cause-effect of variations in a host of structural, financial, political, and demographical variables, and differences in service coverage (Home Help and/or institutional care).

Analyses of local variations in HCBS in Sweden were first undertaken in the 1980s by Berg et al. (1993) and more recently by Trydegård and Thorslund (2001). Part of the concern regarding inequality may stem from the fact that municipal level data have tended to show a lack of association between the HCBS and institutional care. Trydegård and Thorslund (2001), however, found that the proportion of individuals using a service (i.e., coverage rate) for Home Help services were modestly negatively correlated with rates of those aged 80 and above in institutional care ($r = -0.179$). In addition to looking at contemporary associations, Berg et al. (1993) also examined historical patterns within municipalities, and reported fairly high degrees of continuity or inertia on some indicators, a finding echoed by Trydegård and Thorslund (2001) which raises the possibility that local provision is not always rationally (and thus equitably) determined.

A problem with all these earlier studies is that they assumed that needs were about equal in all municipalities and only depended on aggregate data collected at the macro-level, analyses that typically produce low correlations. One exception was a study of Home Help coverage in Sweden, which found a somewhat higher

correlation ($r = 0.29$) between municipal coverage rates of Home Help and rates of solitary living among older adults with implications for total costs for old-age care (Sundström and Berg 1990). As a result this variable was included in the government-imposed formula for tax redistribution across municipalities.

What has been lacking is an analysis that combines macro-level data about the municipal services with information about the elderly individuals living in these local communities. Municipal level data can adequately capture services provided, but are not designed to capture dimensions of individual need so crucial for establishing equity in service provision. For example, as mentioned, solitary living varies, and there are indications of local and regional variations in health and mortality in Sweden which together imply that needs may vary locally. In the United States and Britain, census data indicate considerable area variations in self-care limitations and health (Lin and Zimmer 2002; Young et al. 2005). To assess the implications, we need studies that consider both aggregate level and individual level data; a rare predecessor is a British study that found limited influence of individual need on service use (Evandrou et al. 1992).

If local needs vary significantly, ambitions to provide services in an equal fashion may result in provisions that are far from equitable. At the same time, surveys have found quite small local variations in unmet needs in old people in Sweden (Statistics Sweden 1993) which might indicate that families are 'filling up' the balance and may become overburdened. One study has shown, for example, that public services stagnated in the 1990s but family care expanded during the same period (Sundström et al. 2002). Other research based on individual level data has suggested that Sweden does a particularly good job of targeting those with the greatest needs for services (Shea et al. 2003), and that coordination between formal and informal sectors serves to keep rates of unmet needs low for older adults (Davey et al. 2005). Whether this remains true as services have been further diminished, however, is an issue of considerable contemporary concern (Meinow et al. 2005). Another issue is the balance between what the family and state, respectively, are doing for old people and to what extent the responsibility for old people in need is a shared one. International comparative studies indicate that the degree of sharing varies but is the preferred option everywhere, both by old people and by their families (Daatland and Lowenstein 2005).

Regional variability in home help services has received even more limited consideration in the United States, in part due to the lack of coordination between federal, state, and local authorities in determining the nature and scope of home- and community-based services. Nonetheless, a paper by Egleston et al. (1999) suggests that there may be an association between home help services and the characteristics of individuals placed in nursing homes. From their comparison of two states, they found that the state which spent more on Medicaid

and on Medicaid-financed home help per recipient placed individuals in nursing homes with greater levels of functional impairment, and that this was especially true for individuals living alone. Recent macro–micro analyses by Muramatsu and Campbell (2002) support the idea that state expenditures predict individual care mix, and that those with the greatest impairment may be most affected by low expenditures.

The aim of the present study is to assess whether equality—same service coverage everywhere—is indeed an appropriate yardstick for service ambitions. The suspicion that needs vary locally fosters a more advanced hypothesis: are services equitable? If equity prevails, then we should find evidence that services within municipalities are responsive to the needs of individuals within them, rather than the reverse. Likewise, equitable services will not replace or supplant the available family assistance, although there should be evidence for coordination between formal and informal sectors. Finally, everything else alike, equity implies that an individual's probability of receiving assistance (Home Help) should depend on his or her level of need, rather than the levels of services offered within a particular municipality and that individuals in need of help will have the same chance of receiving Home Help, regardless of whether they live in a municipality with levels of services that are higher or lower than average. Given the possibility of longitudinal changes in their association, we also begin by revisiting the question of whether community-based care and institutional care substitute (i.e., correlate negatively) for one another.

Methods

Data

Individual level data

Individual level data are derived from the 2002–2003 ULF (Undersökningen av levnadsförhållanden [Level of Living Survey]; Statistiska Centralbyrån 2003) study which has been conducted annually by Statistics Sweden since 1976. These are well-known and nationally representative surveys drawn from the population records with a long tradition and with reliability tested in several research projects and in government evaluations of various kinds. The 2002–2003 random sample included a total of 3,552 in-person interviews were conducted with community-dwelling individuals aged 65 or older, with a response rate of 74%; 7% were unable to answer for various reasons, 3% could not be found, and 16% were refusals. The total sample also included 285 institutionalized individuals who were not included in our analytic sample. Because men and the oldest-old were over-sampled, normalized population weights, calculated from those distributed with the data files, were used for all analyses. Overall, then, our community-dwelling sample consisted of 3,267 individuals and was

comprised of 55.3% women with a mean age of 75.6 years (range 65–99).

Municipal level data

Because individuals' municipality of residence (*kommun*) was also known, it was possible to link these individual reports with publicly available information (<http://www.sos.se>) on coverage rates (i.e., proportion of individuals in that municipality, aged 65 or older, who received a particular service). Data were available for between 1 and 285 individuals (mean 12.3) residing in all but one (or 288 of 289) small municipality. Official statistics on municipal old-age care have been collected routinely since the early 1970s, and are considered to be reasonably accurate. Municipalities average about 32,000 inhabitants, with a range of less than 3,000 to more than 700,000.

Measures

Individual level variables

Our primary outcome variable was receipt of Home Help (0 = no, 1 = yes). Individual level demographic variables included age (in years), educational attainment (a 13-category variable from 0 = elementary school to 12 = post-graduate specialization), gender (0 = man, 1 = woman), social class (0 = working class, 1 = upper/middle class), and lives with others including spouse (0 = no, 1 = yes). Number of ADL problems was the sum across seven items (each scored 0 = manages, 1 = needs help) assessing a range of functional domains: “Do you manage yourself or do you need help with—cleaning, shopping for food, cooking, laundry, bath/shower, getting into/out of bed, dress/undress.” Internal consistency for this scale was high ($\alpha = 0.87$). We also had an indicator for being in receipt of informal care for one or more of these ADLs (0 = no, 1 = yes). Our data set also had indicators of whether individuals provided assistance to a spouse or other relative(s), either in the same household or in another household (each coded 0 = no, 1 = yes). We also combined receipt of formal and informal assistance to create a four-category indicator of care mix (informal only, formal only, both formal and informal, and neither) which could include some individuals receiving paid assistance from private sources not assessed in the interview.

Municipal level variables

Municipal level variables included Home Help coverage rates (coded as the number of individuals receiving Home Help services per 100 municipal residents aged 65 and older) and rates of older adults living in institutions (again, coded per 100 municipal residents aged 65 and above). Municipalities were further classified according

to a tertile split as providing low (less than 6.673%), moderate (6.673–8.187%), or high (more than 8.187%) levels of Home Help services. Because coverage rates were generally higher in larger municipalities, the number of individuals in each type of municipality is not evenly distributed.

Results

One of the most fundamental questions in assessing equity is whether municipalities use one type of service (Home Help) to substitute for another (institutional care). These data derive from the national service statistics (115,522 persons who are 65 and above in institutional care, 125,175 persons aged 65 and above who used public Home Help on October 1, 2002). On average, 7.64% of older adults in Sweden receive Home Help, and 7.58% receive institutional care. Interestingly, as shown in Fig. 1, there is no tendency of one kind of service to substitute for the other, contrary to what might be expected ($R^2 = 0.002$).

Related to substitution at the municipal level is the extent to which municipal home help services supplant the support provided by informal support. All of the individual level analyses we present have been adjusted for the nested structure by municipal residence. Again, we find no evidence of diminished involvement of informal networks of individuals residing in municipalities providing high levels of Home Help services. As can be seen in Table 1, a higher proportion of individuals receive informal help from those municipalities providing the highest levels of Home Help services ($\chi^2(2) = 8.06$, $P < 0.05$). As well, it is worth noting that rates of informal assistance are at least twice the levels of these municipal services.

From Table 2, it is clear that rates of individuals living alone are roughly comparable across all levels of

Table 1 Proportion of individuals receiving informal support by level of municipality support (% aged 65 and above who use Home Help) (weighted N)

Informal support	Level of municipal support			Total
	Low	Moderate	High	
No (%)	85.2	85.5	81.3	83.5
Yes (%)	14.8	14.5	18.7	16.5
Total (N)	762	967	1,539	3,267

Table 2 Proportion and number of individuals living alone, and living alone and need help with their ADL (weighted N)

	Level of municipal support (% aged 65 and above who use Home Help)			
	Low	Moderate	High	Total
Percent live alone	39.9	38.0	41.8	40.2
N live alone	304	367	643	1,313
Percent with ADL impairment	20.7	24.6	30.9	26.8
N with ADL impairment	63	90	198	352

municipal Home Help provision. However, many more individuals live alone in the community with ADL limitations in municipalities with higher Home Help coverage rates. In fact, the highest providing municipalities have proportionately nearly 50% more individuals who live alone in the community and need ADL help than do the lowest providing municipalities. Thus, these municipalities differ considerably in the composition of their residents

Another distinct advantage to linking individual and municipal level data is that it is possible to consider how the mix of informal and formal assistance may differ as a function of the level of Home Help services available. The results of this comparison, shown in Table 3, are revealing. First, receipt of informal assistance alone remains the modal category of support, even in a country such as Sweden with high levels of home- and community-based services. Rates of informal assistance alone are highest in municipalities that provide moderate levels of assistance, and considerably lower in the high and low providing municipalities. Rates of Home Help in the absence of informal care are actually highest in the low providing municipalities, and do not differ much between the moderate and high providing municipalities. In contrast, receipt of formal and informal support in combination increases with levels of municipal provision, with rates of formal and informal support approaching those of informal support alone for individuals in municipalities with the highest coverage rates of Home Help. Finally, the rates of individuals with ADL limitations who report to receive neither formal nor informal supports is fairly low (7.6% overall) and uniform as a function of level of municipal support.

One more consideration in the assessment of equity in social services is whether individuals in high providing

Fig. 1 Home Help coverage rates by institutionalization rates ($R^2 = 0.002$)

Table 3 Proportion of individuals living alone and need help with their ADL by type of assistance received (weighted *N*)

	Level of municipal support (% aged 65 and above who use Home Help)			
	Low	Moderate	High	Total
Informal only	36.5	44.8	36.3	38.5
Home Help only	30.9	20.4	22.7	23.6
Both	24.9	26.7	33.7	30.3
Neither	7.6	8.1	7.3	7.6
Total (<i>N</i>)	63	90	198	352

municipalities are more likely to receive a particular service, once need factors are controlled. In order to assess this, we performed a multivariate analysis of the receipt of Home Help. We predicted individuals' receipt of Home Help services using logistic regression from gender, age, level of formal education, social class, receiving informal assistance with ADLs, whether individuals lived alone, and municipal Home Help coverage rates. Our model additionally controlled for the clustered nature of observations nested within municipalities using Stata 9.1. Initially, we considered separate models for men and women, but based on the results of a Chow test ($\chi^2(8)=10.4$, $P=0.24$) they were subsequently combined.

As shown in Table 4, only three variables emerged as significant predictors in the multivariate model ($\chi^2(9)=436.5$, $P<0.0001$). All were related to need. Individuals were more likely to receive Home Help services if they were older, with each year of age predicting an 8% increase in the likelihood of receiving this assistance. Living alone was associated with nearly nine times greater likelihood of receiving assistance, relative to living with others. Finally, each additional ADL limitation was associated with more than twice the likelihood of receiving Home Help. Municipal Home Help coverage rates were *not* associated with individual receipt of Home Help (Odds ratio 1.008). Thus, control-

Table 4 Logistic regression model predicting receipt of Home Help with robust standard errors (adjusted for clustering within municipality)

Variable	Odds ratio	Lower 95% CI	Upper 95% CI
Woman	1.436	0.942	2.188
Age	1.082*	1.053	1.112
Education	0.956	0.866	1.055
Class	0.940	0.634	1.394
Informal help	0.644	0.360	1.151
Live alone	9.087*	4.709	17.538
HH coverage rate	0.815	0.459	1.445
middle third			
HH coverage rate	1.125	0.683	1.852
upper third			
ADLs	2.768*	2.342	3.270
$\chi^2(9)$	436.5*		

CI Confidence interval; HH Home Help; ADL activities of daily living

* $P<0.0001$

ling for need, individuals were no more likely to receive Home Help if they lived in a moderate or higher versus lower providing municipality, consistent with an equity but not with an equality perspective. To assess the sensitivity of our models to how Home Help levels were operationalized, we repeated our analysis using continuously coded support levels. All results were identical, so we retain the more interpretable categorical predictor variables.

Discussion

It is clear that Swedish Home Help services are not equal but it appears that they are indeed equitable, as old persons with the same definition of need have about the same chance to receive Home Help in all types of municipalities, when we consider demand-side variables rather than supply-side aspects. We have not included any of the supply-side aspects of municipalities that were used in the British study of Evandrou et al. 1992, as the indicators used by them make little sense in Sweden. They found that a supply-side factor, high prices of services in 'less supportive' local authorities—a common phenomenon, discouraged potential users. Demand factors, primarily needs as understood by us (needs help with ADL and solitary living), did explain some of the variations but supply-side aspects and especially the price of the service were more significant. Fees remain relatively low in Sweden, and a recent cap has meant waiving them altogether for about a third of users. Interestingly, gender and social class is of no independent consequence for Home Help use in the present study. The British study used data of the early 1980s, when coverage levels of Home Help may have been about the same as today's average of some 5%. It was reported that 68% of 'severely disabled elders living alone' received Home Help. Our category of elderly people who live alone and have ADL problems may be less severely disabled in comparison. According to a much later British study, 20% of elderly persons with 'some level of dependency' use Home Help (Deeming and Keen 2003). In the present study this rate is 37%, which may be due to Sweden then serving 8% of older people, rather than Britain's somewhat lower figure.

Equitable services should give the same help for the same need regardless of locality. A conclusion from the present study, then, is that service levels should vary, rather than be the same in all municipalities, as levels of ADL dysfunctions and living alone vary locally (i.e., equity requires in effect inequality). These variations have earlier not been open to study, as adequate data to assess this have been lacking. The survey data we have used can only describe this in a rather aggregate manner, as census data or other usable individual level data on health or functional capacity are non-existent in Sweden. Countries like the United States and Britain that have census data with information on disability or health have found sizable area variations in self-care limitations

and health (Lin and Zimmer 2002; Young et al. 2005). In the British case, informal caregiving varied substantially in the same way as disability in the population.

The idea that services should vary is somewhat controversial, as equity in old-age care has mostly been identified with equal coverage rates. Though the data used here indicate equity, we regrettably only know whether people use Home Help or not, not the intrinsic quality of the help or how many hours of Home Help clients use. This can be studied at the aggregate, municipal level and there seems to be no connection between the average input of hours to the average client on the one hand, and coverage rates of Home Help on the other hand. Whether this holds up at the client level is less certain. We should have some indicator of quality as well, to better assess the outcome, though few of elderly persons say that they need more help than they get. It is possible that equity in service provision comes at a price, when service hours are rationed in attempts to stretch resources to cover everybody in need.

If, as it seems, Swedish Home Help responds relatively well and uniformly to individual needs, and as has been suggested in previous cross-national research (e.g., Davey et al. 2005; Shea et al. 2003), it remains to explain which mechanism effects such a harmonious response (Thorslund et al. 1997). Why do frail elderly persons who live alone use Home Help to about the same degree in all municipality types? The only explanation we can think of is the strongly engrained Nordic tradition of local responsibility for the poor previously and for elderly people today, surviving in the 'grass roots' Home Help units. These operate with a minimum of bureaucracy and frequently with less professionalism than desired by some observers. They often seem to possess intimate cognizance of local conditions and personal circumstances of the elderly, which facilitates their work to provide adequate services. As long as this organization remains intact, the service is likely to continue to provide good services, or at least to reach out to many needy elderly people in their districts.

Needs assessments in old-age care seem to be somewhat discretionary both in Britain (Evandrou et al. 1992) and in Sweden (Lagergren and Johansson 1996). Knowledge about individual needs of older people living in their district is high with field-workers (Socialstyrelsen 1996) and typically better than at higher echelons, such as the needs-assessors. This may be less of a problem than we think, given the characteristics just outlined. It is for example a fact that easily available coverage rates of the statistical kind used in the present study rarely are used or even known about by administrations, and still less often inspire to any action. From a statistical point of view, random variations in needs assessments are unlikely to invalidate the larger types of patterns described and analyzed in the present study.

It may also be said that, by and large, the results paint a rather bright picture of Swedish public old-age care, in spite of rather severe cutbacks in coverage levels, stricter priorities, and rationing of services in recent

years. In practice services do target a majority of a well-focused group of needy older persons. (Individual municipalities might deviate from this pattern, and still go unnoticed in this kind of analysis.) Equity does not necessarily translate into the same service levels or even the same service mix in all municipalities. Perhaps the difficult question is not one of quantity, but of quality of services.

The present research, the first of its kind to combine both individual and municipal level data in Sweden, necessarily has limitations. First and foremost, we have not included all possible municipal characteristics that might be associated with both services and care mix. Based upon previous research, however (e.g., Berg et al. 1993; Trydegård and Thorslund 2001), we have considered the most proximal municipal characteristics by focusing on the extent of Home Help services and institutionalization rates, standardized by the population of older adults within each municipality. A second limitation is primarily one of measurement. Due to limitations in our data source, it was not possible to construct an ADL assessment with much greater detail beyond the rather simplistic measure used here. Consistent with most large sample survey research, many constructs were measured with a single item, and thus we do not have traditional estimates of reliability in terms of internal consistency. Conversely, our large and representative sample with high response rate does provide us with considerable confidence in the results obtained from these data. In particular, while we know whether individuals receive informal or Home Help services, we do not have information on the extensiveness or sufficiency of these supports.

At the municipal level, we should have greater information about the extent of need for services, and at the individual level, we require better measures of support sufficiency. Related to this, the ideal way to conduct a study such as this is with longitudinal data at both the individual and municipal levels. This affords the possibility of tracking a greater variety of individual outcomes (Li 2005), as well as providing information about the extent to which municipal services lead or lag, and the extent to which they exceed or fall short of need at any given time. Finally, we need better data to help us understand the coordination between formal and informal care networks.

Results from this Swedish study can serve as an ideal starting point from which to make sense of previous micro-level comparisons of Sweden and the United States which have suggested that families are the primary source of support in both nations: families may be more involved in assistance to older adults in Sweden when coresident, but less involved when older adults live alone (Davey et al. 1999); supports are targeted more strongly on the basis of need in Sweden than in the U.S. (Shea et al. 2003); and individuals with the greatest risk of institutional placement receive greater assistance in Sweden than in the U.S. (Davey et al. 2005). It is thus important to know from these more recent data that

even as home- and community-based services have contracted relative to need, these services are still provided in a fashion that appears reasonably equitable and coordinated.

Given that home and institutional services do not substitute for one another, it suggests that services are provided as a function of need within municipalities, rather than the reverse. We have observed a connection between informal care and public services, reinforced when needs are greater. This holds both at the individual level and when municipalities are compared, in the kind of 'natural experiment' used for the present analysis. Regardless of how elderly people and their families may perceive the situation, it implies a synergism where both state (the municipality) and family work towards the same goal and support each other, in a kind of shared responsibility. An increasing number of studies point to sharing tasks between family and state as being practiced in welfare states and also the preferred option of old people and their families in several Western countries (Daatland and Lowenstein 2005). If this sounds excessively solemn, the reality of the practice remains, where both families (and others) and home helpers see to the needs of elderly people. Public support to carers can be indirect, such as home help and other services. Direct support to carers is much less common and very uneven when available. An improvement is under way due to new legislation, and some municipalities do provide considerable direct support to carers, but many provide little or none (Johansson and Sundström 2005). In conclusion, we have found considerable evidence that persistent wide variations in levels of home- and community-based services for older adults appear to reflect actual differences in levels of need between municipalities. Once these need variables are controlled, individuals in high service municipalities are no more likely to receive assistance than comparable individuals in municipalities providing low or moderate levels of assistance. Thus, we conclude that Home Help services in Sweden remain largely responsive to their constituencies despite recent contractions in service levels and are distributed unequally, but equitably.

Acknowledgements This work was partially supported by a grant from the National Institute on Aging (R03AG023301).

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