

# Mediation, Non-Participation, and Technology in Care Giving Work

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## ABSTRACT

Demographic changes are placing increasing emphasis in Nordic and other countries on the provision of care for elderly and other people in their homes. In this paper, the possibilities for a group of home helpers to act as mediators for the needs of assistees is discussed within a context of the changing information technological regimes of the local government.

## Keywords

E-governance, IT, democracy, political mediation, public services

## INTRODUCTION

Democracy at work was the major interest behind the establishment of what today is known as PD [2, 13] and for many contributors, remains so (e.g. [7]). Meanwhile, the spread of computers from the workplace into new domains (e.g. homes, schools) and in purposes (e.g. entertainment, shopping, advertising, and governance) has also widened the scope for PD interests. To deepen the understanding of these situations, however, Participatory Design needs to be supplemented by other approaches [5]. This paper is a study of lack of participation in care giving work. The backdrop is a municipality aiming at societal transformation using IT.

Widespread interest in "e-governance" [e.g. 8] appears to have combined with concern about demographic changes to make policy makers across Europe give increasing attention to the provision of care for elderly and other people in their homes. The potential of IT in enabling more assistees to be cared for at relatively lower cost is a current topic of research including several projects funded by the European

Union. Meanwhile, the literature on effects of the information society has raised concerns about inclusiveness for vulnerable or marginalized people. This has often taken place in terms of a "digital divide" of haves and have-nots, leaving unaddressed the question of conditions for altering their situation [6]. In the present paper the above concerns are combined by exploring the conditions for participation in the provision of home help care and how this may change with IT. The focus is on the potential for home helpers to hear and to communicate concerns of assistees. As shown below, this is conditioned by home helpers' possibilities of being heard as well as by the technical-organizational environment in which they conduct their work.

## Ronneby and its Home Help Service

During 1992-2001, central officials of the Swedish municipality of Ronneby oriented to "IT-samhälle" (Information Technology Society) as an ideal for citizens and for governance starting from the formal adoption of a visionary document as municipal policy. The stated aim was to develop a society in which all citizens were familiar with IT (later modified to all municipal employees); which was to be known as such; and which consequently would attract software industry and workplaces. Existing and potential tensions between sections of the population were addressed in the vision document and special efforts proposed to smooth these out. Ronneby was to be a nice place to work and to live and IT was to be the means. The project which the present study is a part of aimed to understand how this ideal affected citizens and to what extent and through what means citizens may influence the aims and outcomes.

To explore the above question for service provision, a study was conducted in the Home Help Service: In Ronneby and throughout the Nordic countries, elderly and disabled people may receive necessary assistance from the Home Help Service (HHS). This is a municipal service to enable

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continued living at home. With roots in informal care giving networks [17] it is meant to complete these where they are inadequate (as assessed by HHS officials). The cost is primarily born by municipal tax income and the remaining fee depends on the income of the assistee and hours of assistance received.

### **Mediation**

The paper examines the potential of home helpers to function as “mediators” for elderly and disabled citizens receiving home help in Ronneby. Rather than employing one of the numerous theoretical explorations of mediation, it uses a political concept of mediation focused on influencing decisions, in this case decisions about service provision and technologies that influence it. Mediators, in this sense, represent or carry forward concerns of one group to another; typically to a powerful group. Madon and Sahay have studied the substantial achievements of a non-governmental organization (NGO) in facilitating the concerns of a vulnerable group being carried forward to their local authority. In [12] they propose some ‘mediation models’ for analyzing information flows between citizens and government agencies. Although proposed for NGOs these open some interesting issues for the roles of the HHS in Ronneby. *Partnership of NGOs with government* involves, centrally, the incorporation into governmental efforts of lessons from NGO experience. This necessitates channels of communication between NGOs and government through which advocacy could be exercised. By *partnerships with commercial* organizations, Madon and Sahay understand strategic alliances between NGOs and companies, particularly where government fails to fill the need. When *acting as service providers*, professionalized NGOs work closely with government, perhaps with explicit contracts. While institutionalization of NGO work may ensure it gets done, such arrangements may weaken critique of underlying structural causes for its need. *Advocacy* has resulted in many successes for NGOs through lobbying, publications, networking, etc. The *accountability* of governmental officials is proposed by Madon and Sahay as the key to achieve changes through pressure from citizens and citizens’ organizations.

### **Studying the Home Help Service**

This paper is based on field work conducted during 1996-2001 in the Home Help Service in Ronneby. An initial interview study with supervisors and managers [3] had found a continual balancing of the needs of care provision against those of economics and efficiency. IT, while in daily use, was almost exclusively employed in service of the latter. To learn about how “IT” was experienced by people who provide care and who did not take computers for granted I next turned to home help assistants, focusing on a workgroup which had been designated a pilot group for IT for home helpers. The empirical method for the home helper

study may be described as a series of small ethnographic studies in which the researcher made intermittent visits to a single group of informants. A few points are worth noting:

First, each visit lasted 1-10 days, the majority of which entailed 3-4 abbreviated days. The aim was to understand more of the character of this work and how the prospect and actual use of information technology shaped it and was shaped by it. Together, these visits constitute a study of work processes under changing conditions of computerization. Over the years the group changed in various ways. Changes included a substantial change in membership and changes in pressures on the group. The latter seemed to peak around 1998.

Second, my approach has been to understand the nature of the work of home help assistance by listening and watching, by experiencing it to the extent I could, and by asking questions. I was present during the morning meetings at which the schedule for the day’s work was laid or finalised and during a number of conversations between assistants. Opportunities for initiating conversations arose at the group rooms (e.g. during breaks and after meetings) and while walking or driving with assistants. Traveling to assistees together also provided the opportunity for assistants to initiate conversations with me.

Third, during my visits I have taken part in the daily work—although less than fully, hence my hesitation to apply the term “participative observation.” I have accompanied one or two assistants at the time on their rounds, visiting assistees and helping out where I felt I could. My interest in better understanding the nature of the distance I sensed between myself and my informants led me to broaden my focus from merely questions about their (somewhat ambiguous) relation to a PC in the group rooms to inquiring into the conditions under which their relationship to a host of changes (including the introduction of the PC) made sense. Substantial lack of opportunity for informants to participate in decisions affecting their work situation was evident early in my fieldwork. This paper is a result of analyzing causes and consequences.

Fourth, I have relied exclusively on field notes; quotes in the text are not to be taken as literally precise (subtleties are also lost in the translation). Conversations with home helpers were not automatically recorded, initially because they did not give such permission. Later I grew to enjoy the absence of a tape recorder because it forced an approach more focused on joint experience. Nevertheless, our relationship has been highly asymmetric. This is particularly the case with respect to the analysis but also evidenced by my speaking, frequently, of the “group” as if a uniform entity rather than individuals with various concerns and approaches to the work. Comments such as “what’s she writing now?” have, however, provided opportunities to

make available to informants more of my method of working and foci of attention. At times I invited comments from the group on emerging topics including the lacks in participation, which deepened my understanding.

Fifth, my own bewilderment at meeting care work in its at times unpleasant guises has been an important source of analytic questions about difference. Interested readers may read Isaksen's theoretical treatment of effects of the taboo associated with others' bodily fluids on care work (paid and unpaid) and on her own analysis [11] as well as my reflections on the distance between care work and computing [3] and on bafflement as an analytic tool [4].

Sixth, the field work provides highly limited insights on assistees' perspectives. This has implications for the scope of the discussion in this paper which focuses on the service provision. In Ronneby I have come across no attempts to facilitate assistees speaking for themselves on the service they receive. Some are unable to, but many address their grievances to those they meet: the home helpers. For these reasons, the home helpers bringing forward more of their views on assistees' needs would be an advance. Thus, while mediation may seem a modest aim its value lies in its potential to facilitate full participation.

#### **VULNERABILITY**

My exposure to assistees made vivid that a diminishing health has specific consequences, the impacts of which are not to be belittled. For some, poor hearing or eyesight leads to difficulty in engaging with familiar sources of information, inspiration, or participation. Poor mobility cuts others from familiar locations for meeting people. Additionally, for those receiving help from the Home Help Service, the inability to look after oneself or one's home may itself bear consequences as may the prospect of eventual "incarceration" in an institution. The latter was evidenced by some assistees' explicit misgivings. Other studies have found considerable strain from drawing on the resources of relations and neighbors over years [11] and strain even on professionals in prolonged, close relationship with people with senile dementia [14]. In exploring care-giving for elderly people who have lost control over some of their emptying functions Lise Widding Isaksen describes control over the body as having become an area of performance in contemporary society, causing extra pressure on elderly people and on their care takers to hide failing control [11, p.9]. Isaksen has reflected on failing social networks as one consequence and on the low status and salary of "close-to-body" care work as another. Extending Isaksen's argument, attributes of age such as life experience, wisdom, etc. are not prominently valued in contemporary Nordic societies; instead, "adaptability" and quick learning, physical beauty, knowledge of other places and of technology—i.e. attributes of today's youth—are.

Home care recipients (assistees) in Ronneby can thus be expected to be liable to exclusion from dominant society by virtue of failing health and their age. Vulnerability, a term used in Development Studies (e.g. [10]), may help explore some of the potential and actual difficulties experienced that influence the lives of home care recipients and which ideally would influence relevant government policies.

Some elderly or young people who can no longer fully look after themselves appeared to find the help of the Home Help Service easy to accept while others expressed resistance. Individual assistees expressed appreciation verbally or through offering assistants e.g. a cup of coffee and resistance e.g. by addressing assistees in abusive terms. Explanations may include differences in how the service is actually offered, but it also seemed that some found it hard to accept a fate of considerable reliance on others while others did not, or they considered the service their right (e.g. as a tax payer or as a senior citizen). By virtue of having to accept help, I label all vulnerable with respect to municipal service provision. It is important to remember, however, that vulnerability was a specific aspect of the situation of a care recipient. In taking this perspective I exclude many of the resources—personal and social—and sources of joy that were also in evidence when visiting assistees.

#### **WORKING BETWEEN VULNERABLE CITIZENS AND THE MUNICIPAL AUTHORITIES**

My argument is that the home help visitors (home helpers) are in an "in-between" position with respect to, on the one hand, elderly and disabled home help recipients, and on the other, the municipal authorities and their policies. This builds on their closeness to assistees.

For some assistees the regular visits of the Home Help Service provided the bulk of their interaction with others. Many kept informed about and interested in those who assisted them, asking e.g. how their children or husbands were doing.\* Generally, relationships were based in and strengthened through repeated contact about everyday issues such as assistees' personal habits, difficulties and how they handle these; their preferences, e.g. what bread they like or what cat food to get; and assistees' relations to relatives and friends. For a few assistees, the District Nurse and the HHS supervisor had allocated time also for sitting down and talking for a few minutes. The fieldwork clearly showed that more contact between an individual helper and assistee meant more knowledge and usually also a deeper mutual understanding. For example, I experienced substantial differences in how assistants dealt with assistees (particularly those considered "difficult") and the extent to which they were able to prepare different kinds of space for my presence depending on who we were visiting. , e.g. informing me about assistees we are to visit and

preparing me for our joint work with the assistee. Comments could be "you could go into the kitchen and start preparing breakfast," "S. will enjoy meeting a new person today," "I wonder what mood R. will be in today." I have been much heartened by the care and subtlety with which, I eventually realized, not only assistees thus were protected from my potential intrusion, but also I was protected from assistees in a less than sociable state of body (e.g. while preparing to shower someone wearing diapers) or mind (e.g. while waiting for caffeine, tobacco or medication to take effect). Both the skillful provision of service—including such subtle management of breaks of cultural taboos [11]—and, it seemed assistants' satisfaction with the work despite its unpleasant sides, relied on mutual familiarity developed over time. This was recognized in the HHS policy of assistees having the same assistant visiting when possible.

Home helpers could be heard lamenting not having more time at their disposal to talk or sit with assistees because they recognized addressing deep needs for human contact as an important part of their work with respect to many assistees. Some relationships between home helper and assistee entailed mutual joy—and given more time together, more of them probably could do so. In other cases the recognition of their role as part of a relationship was evidenced, e.g. by someone invoking the difficult life situation of the assistee during conversations that centered on some recurrent difficulty: "But of course, it's hard for him to live like that, with ... (various ailments)." Often, this would bring the discussion to an end.

The position "in-between" assistees and municipal policies operates in at least two more senses. First, they provide the service itself as employees of Ronneby municipality, thereby constituting one of its interfaces with the public. In this, they also answer questions that may turn up, thus mediating queries and constituting a channel of communication. I have mostly seen this in two ways: On the one hand, pre-emptive, where the home helpers initiated conversations as vehicles for helping, e.g. about health issues or the birthday of a relative. In so doing they created opportunities to subtly remind someone of an appointment, check the person's understanding, or offer relevant information. On the other hand, as "fellow citizens" they were expected to know, or potentially know, about events, changes, etc. I have seen home helpers initiate conversations e.g. about the season, forthcoming social events, close relatives, etc., telling me afterwards that this assistee particularly benefited from having their interest aroused, and I have seen assistees ask the visitors, e.g. about Christmas decorations in the street.

The second sense in which the home helpers are "in-between" policy and assistee is through their shaping of the service they provide. This showed, among other ways,

through the home help visitors engaging in continuous negotiations with recipients over work limits and expectations. According to the fieldwork, the extent to which this was needed and how it was handled varied considerably, not least depending on the personal relationship between helper and assistee. This, as the above, is one of the axes around which relationships evolve, between home helper and assistee as well as between home helpers. Experienced home helpers were highly skilled at such interactions with assistees—including not only smooth handling of contrasting positions (i.e. of potential conflict), but also pre-empting their arising: Through shaping expectations of assistees, often in subtle ways, positions were aligned by encouraging certain expectations from assistees and discouraging others. At times I heard difficulties expressed to colleagues and to me, out of earshot of assistees. This seemed to enable limited "venting" of difficulties while shielding assistees. Sensitivity to and understanding of the strain under which many assistees were forced to conduct their lives marked many such conversations. Only a handful of times have I witnessed rules being evoked in front of an assistee to support an argument. Thus, limit setting was mainly handled through skillful guiding of conversations towards what is to be understood as "reasonable." This may be termed "mediating for recipients' reasonable expectations."

The position of home helpers as mediators between elderly and disabled recipients of municipal services was at times fairly uncomplicated—basically when the support system was working as intended and recipients accepted its limitations. In high pressure periods, however, home helpers faced difficult tradeoffs. I saw many examples of trying to distribute the strain; reducing own breaks, postponing non-urgent work, and passing on some of the grievance to their superior. The supervisor often refused to address the situation, saying she was locked by her budget (e.g. when refusing to call in replacements for staff absences, or calling in fewer replacements than those absent). Thus, their possibilities of actually resolving such situations by removing the strain was minimal, as the recurrent source of problems was staff shortages over which they had no influence. Thus, in contrast with the subtle skill with which many potential difficulties with assistees were avoided, other aspects of shaping the service appeared to be considerably more troubling. In question was resistance against being placed in a position of mediating unreasonable expectations—i.e. the home helpers were expected (by "the system," represented by superiors) to keep providing a reasonable service, without having the staff resources to do so. The pressured trade-offs led to difficult discussions among the home helpers where several loyalties were in conflict: To the supervisor/the system/the municipality and its need to save money (e.g. when a home

helper advanced an argument to colleagues emphasizing understanding of why the group is short of resources), to immediate colleagues (such as trying to split the work load fairly between them, but by which criteria), to own rights as employees (including responsibility to own family needs, or other resistance against getting too tired), and to help recipients. Perceptions that colleagues were not prioritizing assistees sufficiently led to the strongest intra-colleague conflicts I saw. This occurred during a period when it was often impossible to make the daily schedule come together. Although many home helpers regularly gave up their breaks bi-weekly cleaning was repeatedly postponed due to staff shortages. Assistees made few formal complaints although home helpers sometimes encouraged it. Conflicts arose over how long to accept such a situation and to whom and how to react when it was felt the limit was reached.

The complex tradeoffs arose when the system did not work as intended. Several axes of concern mix such as the needs of home helpers as employees (with rights to a lunch break, and not to work overly hard) clashing with the statutory rights and “humane” needs of recipients. Dealing with this as part of everyday, regular work also entailed a partial hiding of these difficulties from others.

#### **THE “BETWEEN” POSITION AS MEDIATION**

Before discussing roles of technology, I next explore mediation. Being employees of the local government authority and carrying out services it is required to provide, home helpers were liable to act, and to be received, as its representatives. “Representation” was reinforced e.g. by their cars for a while carrying the municipal shield and name; also, in the ongoing negotiations with assistees discussed above, limits against other municipal bodies and services were often in focus. Home helpers, thus, were required to carry out and at least partly defend decisions and structures of the local authority. (I have seen the home helpers outwardly defend the system, despite internally expressed misgivings). It is this complex interrelationship I wish to explore using the models in [12], presented above.

*Advocacy:* The question of advocacy in the Ronneby study is whether the home help service could have an advocacy role for elderly and disabled citizens at least for issues concerning the assistance they receive. I argue that home helpers occupy a position from which they could and partly do act as advocates (but highly subtly and in limited respects, the impacts of which are uncertain). In my analysis the Home Help Service operates in a hierarchical way, contributing to a lack of openness to two-way negotiation between those lower on the rung and the managers. Complaints have consistently been made in my presence over the years by various home helpers in this group that their professional opinions are not valued by others in government; including their immediate superiors (“They

don’t care”). While initially I found these complaints disturbingly polarizing, over time I understood how such a perspective had had fertile grounds for blooming in the meetings between supervisors and home helpers.

For example: a) When having to change group rooms, group members themselves were engaged in finding a new venue, telling me they had been asked to do so by their supervisor. Eventually a suitable location was found. Then, however, they found the supervisor not open to their suggestion after all, as other (free) rooms had been decided on. This had not been communicated to the group whose members had spent considerable amounts of time and effort finding a place that was suitably located and sufficiently economical. Group members were not happy about what they experienced as off-hand and unpredictable treatment by their superior. b) At another time, when the coffee machine in the group rooms needed replacement, money was only granted for one of second quality. This was felt by home helpers as a sign of disrespect, especially as the amount saved was small. c) In 1998 I was present once when the supervisor visited the group rooms. After some general talking she announced that she had cancelled the agreement with a security company that provided the secure key tag service they had been using. Upon hearing this, surprise was voiced and questions rose as to how they were to securely keep track of the many keys kept to assistees’ homes. The response was that it was necessary to save money and “I’m sure you’ll work out a solution.” After the brief meeting home helpers confirmed to me that they had not heard of this before. An alternative solution was worked out, but the episode added to the impression of a non-participative style of management. d) In 2000, when asked for feedback on my analysis that they don’t get to take part in many decisions that affect them, one home helper exasperatedly said that home helpers are continually told of the need to save money but initiatives from home helpers even within this area are unwelcome. She told me the following example: Once she suggested a cheaper way of obtaining disposable gloves but this was not welcome as the HHS had an agreement with another vendor. In itself she found this easy to accept, but not the disinterest she felt met with: “Contracts come to an end—won’t this one too, at some point?”

A pattern emerges in which the group is, on the one hand, asked to take responsibility for resolving issues (both regular, such as daily scheduling even in face of understaffing, and ad hoc, including issues that arise from supervisor decisions), and on the other, may be overridden at any time by the supervisor. While we may safely assume that the supervisor is acting according to her concerns, which may be important enough and understood in light of the pressures she faces, of primary interest here are the effects on the home helpers, in particular on their ability to carry forward their concerns for assistees.

While I have only interviewed in this group, there is reason to believe dissent to be widespread. At one point my informants discussed refusals by colleagues in a nursing home to comply with new regulations and threats of industrial action by a different home helper group. The latter made it to the local paper: Causes given were the lack of a promised pay rise and lack of patience with an increasingly difficult work situation including rising numbers of elderly, more heavy work, more tasks (including alarm handling), a new educational requirement, and stricter regulation of what they were and were not permitted to do for assistees (notably threats of job loss if regular breaks of the new rule not to shop for assistees who do not accompany them was detected). In reference to the latter, assistants are quoted as saying: "The fact that we work around this by giving a hand during our spare time is no-one else's business." [14] The new restrictions on shopping and cooking for assistees roused considerable grievance also in the group I visited. These reactions contrast sharply with views on what constitutes home help assistance in some technology-focused research and development, including [1, 9]. E.g. Heikkilä et al. assert: "Any relief in the burden of daily shopping may make it possible for the home helpers to concentrate on duties they are hired and trained for, and for the elderly to gain access to [a] wider selection of services." [9: 338].

To date, then, the study has uncovered no effective channels for advocacy within the home help service in Ronneby or long term plans that would change this. A 2-page form does exist for recording, with the participation of the assistee, her capabilities, wishes, and resources current and needed. I see this as a convincing tool for eliciting and recording such issues and it could be used as a tool for advocacy. However, I have only seen such forms at a supervisor's office and not in the hands of home helpers. Further, home helpers do not have authority to initiate action to meet the goals. Thus, while this form seeks to strengthen the position of the care recipient with respect to the service provided, those in the service with most contact with her may only carry out practical aspects as decided by others. The impact of this form, then, is highly limited. A further channel is the general possibility to call the supervisor and discuss issues. In practice, however, this seems to me under-used even to complain about lacks compared to the agreed levels of service, so I consider this an unlikely candidate for a channel for serious discussion of the terms of the service itself. In conclusion, worthwhile initiatives such as the form notwithstanding, responses to the service provision as such and its terms do not seem encouraged in any channel.

The above identifies a need for effective communication channels *within* the government, between those in closest contact with a vulnerable group and decision makers. In

terms of the NGO situation with which Madon and Sahay's paper is concerned, the above indicates a need to diversify discussions about government: The strain and differences evident between employees of government in the Ronneby case poses the question of *whom*, or what interests of government we are talking about (as opposed to government as such).

*Accountability:* While corruption is not considered a problem in the home services in Ronneby, other issues of accountability could be. Assistees may hold the nearest government employees accountable to the extent they talk together—and my sense is that several elderly tried, subtly, with the home helpers—but these are not decision makers. Thus, the system has "accountability," but it is hard for an individual to locate as it is frequently "elsewhere." While at each level municipal employees appear to be doing their job properly the question of whose concerns are to shape what that means, keeps receding into the horizon.

*Partnership with Commercial Organizations:* This model is not applicable, yet provides interesting points to consider. Partnerships with commercial organizations is looked to by many who influence policy in Ronneby and elsewhere as providing solutions to some current and expected future challenges for the Home Help Service. This is a key interest for the present project and is further discussed under "Technology" below.

Already, agreements with commercial organizations, e.g. for exclusive deliveries of disposable gloves, help mediate the existing structure of the Home Help Service. Being a sizeable bureaucracy, agreements are made with the Government as such, represented by the relevant branch, i.e. the Home Help Service, represented by managers. Such agreements can facilitate evasion of participation, by in effect freezing beyond questioning a number of details that shape tools, and therefore work practices, of home helpers. If there is no participation in the decisions and negotiations leading up to agreements with third parties they lend themselves to reinforcing hierarchical domination through the receding accountability discussed above.

*Acting as Service Providers:* While at first sight nonsensical—the Home Help Service *are* the local government's service provider—this mediation model raises the question of the effects of institutionalization. The service originated in the practices of extended families and of neighbors looking after people in need; this was gradually institutionalized with pay, formal employment, etc. (for the Norwegian case, see [17]). Established to complement other networks and services, the HHS is in some senses meant to be complete and for all. While providing a much appreciated service with considerable stability and dependability, being part of government also entails constraints (notably, budgetary) originating outside

the relation of helping. The resistance against new regulations, then, may be an indicator of the partial failure of the institutionalization; the difficulties in being heard and bringing forward concerns for assistees may be an indicator of its partial success.

An interesting question is to what extent Scandinavian welfare models have assumed both their own completeness and the ability of government welfare agencies to advocate for their users/clients. There may be a paucity of research that facilitates understanding of long-term issues for clients [16, p.137].

In conclusion, home helpers do seem to be in a position in which they might act as advocates for assistees. Yet, there is little evidence of such a role being enacted. Could new technologies change this? The next section examines existing technologies and the potential of more ICTs.

### **ROLES OF TECHNOLOGY**

Home help as currently understood is inconceivable without a number of artifacts we might think of as “technical.” They played three major roles in the work of the home help group I have studied. First, technical artifacts were used for mobility. Distances between homes covered by this group necessitated the use of cars and bicycles for transport as well as walking. Thus a fundamental premise and requirement was the mobility of staff and technical aids to ensure it. Second, in the homes of assistees there were technical aids over and above those usually expected. These included chair lifts, alarm devices, and wheelchairs. Thus, technologies that may remain the property of the municipality or of some other body, or may be the property of the person using them, are a second given. Third, various technologies enabled the home help service to present itself as a coherent service, as part of a network. These are in focus here, partly because they are contested in the service (through problematic introductions and usages) and partly because such technologies are my research concern.

#### **Technologies of information**

A considerable number of “information technology” devices were in use at various points of the service. Focusing on the home helpers’ work, these included telephones (stationary and mobile), various paper based repositories, a whiteboard, and a PC. The group rooms had a telephone which facilitated (stationary but remote) communication, frequently with supervisor and district nurse. Also in use were mobile phones, both official (for the “alarm”) and private (for coordination of mobility—being picked up by colleagues in a car nearby). Various paper based repositories were central to the organization of work. The work of distributing the day’s work was organized around an A4 pad on the large table around which the morning meeting took place, in which the daily schedule as it emerged during the meeting was recorded (with a careful

alternation between pen and pencil to allow maximum ease of alteration during the meeting and later). Small strips of paper were used by each home helper to record her or his duties of the day, affording economy of recording and maximum mobility. A notebook for writing down messages about a specific help recipient for the use of the District Nurse (who may or may not read it) had also in periods been kept on the table. Various forms and memos recording schedules for each employee, changes to practices or rules, social activities, courses etc, resided in a folder on or near the table. The whiteboard, prominently visible from the table, found two main and interconnected uses. First, it held messages. These mostly concerned various recipients, e.g. this person is going for X-ray on such a date and time [I have seen numerous such messages on the board] or that person was admitted to hospital last night [this I have rarely seen, despite or because such news received full and at times prolonged attention in group room conversations]. Also messages about car maintenance and, e.g. my arrival. Second, the whiteboard displayed staff working schedules summarized for the week (overall view summarizing who was on duty each morning, afternoon, and evening). Thus, the whiteboard assisted coordination between days, affording easy view of events in the near future. A new arrival as of mid-1990s was a PC. Its purpose was unclear to group members at the start of my field study with them, around one year after its introduction—and remained so for a considerable time (years). By 2000 it had finally gained a purpose recognized by the home helpers as relevant for their work: A system had been implemented for receiving messages from the hospital about discharges of assistees. Assistants, however, never received adequate training.

#### **Distance and communication**

All the technologies which formed part of the work environment of home helpers, described above, had in some sense the purpose of helping assistants help assistees to remain living at home. Only one cluster of technologies did so directly: the second one (lifts etc). Another cluster of technologies, those enabling mobility beyond walking, was necessitated by the current centralized organization of the work. A joint assumption behind these technologies was the desirability of co-presence (one assumed it, the other enabled it). In contrast, those technologies that I above refer to as a third cluster (facilitating the Home Help Service as a system—whether paper based, phone, or PC), assumed and enabled a centralized-distributed pattern of information and of work (i.e. distributed presence controlled or coordinated from centers elsewhere). In this sense, the former technologies afforded the development of relationships between home helpers and assistees; the latter afforded distancing. The technologies of mobility transported and transferred home helpers between these realms: Crudely put, when home helpers left the group

rooms and got into their cars, onto their bicycles, or started walking they were also leaving “bureaucratic” organization and entering “relationship” as the dominant voice. These were not separate. On the contrary, field work to date indicates recurrent tensions between these concerns. Most time was spent in the “relationship” realm, but in case of conflict, the realm of “bureaucracy” was meant to have the final say (it did not always do so, as complex judgments including those of moral right entered the scene). The different natures and purposes of these clusters of technology go some of the way towards explaining the multi-faceted relationships between members of the home help group studied and the technologies they were, or could be, using; in particular the ambiguous relationship to computer terminals.

A “technology” (or “network” or “service”) that demonstrated the integral nature of interconnections between the organization of work, technologies in all three categories above, and external conditions in the provision of service, was what I may call the alarm network. This consisted of alarm devices placed in the homes of subscribers (a phone and/or large push button); the alarm center (basically a specially trained switchboard function: the person at the center communicated with the subscriber who had sounded the alarm, decided if assistance was required, and if so, initiated help by calling the home helpers); and a mobile phone (carried by home helpers and referred to as “the alarm”—as in “Who’ll take the alarm today?,” a question frequently heard after the morning meeting). Until and including my 1998 visit this was a local network geographically located within Ronneby municipality and organizationally located within the municipal Home Help Service. The alarm center was staffed by a supervisory official of the Home Help Service. By my next visit in late 2000, the alarm service had been further centralized; alarms now went to a regional alarm centre located in a different city, who called the home help mobile phone. This caused problems as the regional center was considerably busier and its staff rarely had knowledge of Ronneby or of how the Home Help Service worked. (By late 2001 these difficulties no longer troubled informants.) These changes were yet another example also of the lack of influence by home helpers over decisions that may considerably change some part of their work, even when the new model of service provision requires—as in this case—additional effort from them or a poorer service or both.

The above description of the changing alarm network shows, further, an example of the continual changes in the technologies themselves, the work processes around and with them, and the context in which they are used. This applies more generally, in a complex interplay of elements. Information technologies may be particularly volatile and the causes for change hard to untangle. For example, after a

move to new group rooms the whiteboard saw less use. Reasons could include the white board being more awkwardly placed; the “break” area now being in a different room, taking people more away from the whiteboard; the staff shortage being less pronounced; or a representative of the new supervisor having started to attend morning meetings, thus reducing the need for written messages.

#### **Information and communication technology (ICT)**

As alluded to above, ICT is often held to deliver great promises for the future of home help service provision. A combination of IT and service delivery companies are to make the service more efficient. Early experiences, however, call into serious question the roles assigned to assistees in the development schemes. Moving from visions to attempted implementations within a few years, the scope of concerns seems to exclude voices of assistees, their relatives, and also their potential advocates. In these efforts—much talked about in the Nordic countries—the advocacy role discussed above seems to retain no force. The increasing numbers of elderly people during the next 20 or so years and the impossibility of dealing with them with today’s service appear to be powerful arguments for a focus on economics. In Sweden an example is [1], a report produced by organizational consultants with the participation from HHS supervisors. This report proposes wide-ranging changes for the Home Help Service to become more ‘efficient’ by splitting it up and introducing e.g. motor cycle deliveries and prescriptions directly from doctors’ offices to pharmacies. In it, little or no consideration is given to how to arrive at this scenario or to the difficulties of transition and the possibility of extending the service along other, arguably more humane lines do not figure in the discussions. Its expectations that time saved in the Home Help Service would be spent talking with assistees seem naïve considering staff complaints of a general intensification of the work (e.g. earlier discharges from hospital led to savings elsewhere; the heavier burden on the HHS was never adequately compensated). Previous experiences in the Ronneby Home Help Service of inadequate training in IT similarly weaken trust in such projects. Heikkilä et al. also propose splitting up services through IT in their comparison of shopping done by home helpers and through other means. They conclude: “The home helpers’ time, that will be released through the use of more sophisticated and time efficient models of grocery shopping, can be used to increase the personal contact time with current customers or to provide services to additional customers.” [9, p.348] While Heikkilä et al. acknowledge this being “a social political decision,” both [1, 9] beg the question of what the basis of ‘personal contact’ is thought to be if shopping, cleaning, etc. are removed from home helpers and carried out by various specialized delivery and cleaning contractors. In contrast, the field work has shown



the relationships mostly to be constituted precisely around such mundane tasks.

#### **IMPLICATIONS: RELATIONSHIPS, THE HOME HELP SERVICE, MEDIATION, AND IT**

The personal contact, the extensive knowledge of assistees' difficulties, and their sensitive hiding of the intimate details of associated breaks of cultural taboos, form in my view a powerful basis of the mediation potential of home helpers: there was compassion, understanding, and mutual trust. This mediating potential was being realized in terms of tailoring the service provided, but for reasons detailed above, less so in terms of shaping the conditions for it, or of otherwise reporting common concerns of assistees to others sectors of the municipal authority.

To the extent that the home help service is expected to provide for elderly and disabled citizens in need of municipal assistance to keep living at home, the service may have a mediating role between needs of assistees and the public responsibility to ensure it is met. A proviso in this line of thought is the willingness to place centrally the needs and rights of citizens/assistees, rather than, for example, the financial imperatives of the municipality. While the former is unambiguously stated as the grounds for the Home Help Service in Ronneby, its practices are observably also conditioned by the latter [3]. The mediation focus provides some interesting perspectives on the gaps between the potentials of the home help service and what it in practice is left to do for the elderly. Taking the mediation models as a starting point the service has been identified as having potential as mediators, and failures in realizing this potential are partly structural, partly contingent. Altogether, the home help service has the potential to be an effective mediator between concerns of those needing help at home and the government, but appears to fail on several points. Primarily, those who are closest to the assistees are made to only deliver, not shape the conditions for the service. These are rather determined by others who physically and in terms of concerns are more remote from the assistees. Secondly, they are not given the staff resources to perform as well as they feel they could and should. Staff shortages cause excessive staff rotation and outright postponement or cancellation of promised services. Both erode trust and weaken relationships. Root causes of failure to realize the potential advocacy within this local government agency thus seemed to be the imperative to save money and a hierarchical culture, in which initiatives from those with most contact with assistees were undervalued. In this light municipal efforts at improving services to citizens through increased use of web applications ("24-hr government") seems to stay with surface problems.

The key issue for change with technology-facilitated reorganization of the Home Help Service is whether the

opportunity will be taken for visionary organizational changes that facilitate advocacy and participation. Sadly, indications are that the shortfall situation seems likely to deepen in the future. Services are gradually fragmented; more people are dealing with each care recipient resulting in smaller surfaces of contact and severely reducing the possibilities of developing mutual understanding and channels of communication.

The question of the ability of home helpers to realize their potential as (partial) mediating advocates for elderly and disabled citizens in Ronneby municipality has repercussions beyond Ronneby. This study has been an example of the distance of PD from institutionalized practices of employment, accountability, and authority in a Scandinavian local government service.

A technology lead in Home Service development projects is all the more serious as IT is expected to solve mounting pressures on the home help services and appears to be the dominant heading under which change is considered. In contrast, I hold that IT has the potential to bring a range of improvements to home service shaping and delivery that would support the mediating potential of the home helpers for those in need of assistance at home. This requires a different starting point, however, focusing on assistees' expressed needs and how best to elicit and shape the service by them. IT could, then, be put to new and unimagined uses in the Home Help Service. Concerning *organization*, home helpers "on the ground" would need to be placed centrally in the development teams (Participatory Design techniques for the participation of people with more skill in the work concerned than in computing have been developed and could be put to use). One might also ask right from the start how issues of scalability will be dealt with. If the start is a limited project, how to extend the development work in time and place to encompass the daily provision of this service? Could other ways than "projects" be imagined for a development effort? Concerning *topics* for such "alternative" uses of ICTs, one starting point might be the fundamental importance of one-to-one relationships in the Home Services of today: If this is to be valued as an aspect of the Home Help Service of the future, how can ICT facilitate the development and sustenance of such relationships? Answers to such questions might range from applications of existing technical solutions (maybe email), to hitherto unimagined ones that might provide a challenge to existing conceptualizations of computing development. A different starting point might be the continual trade-offs between different concerns, including imperatives to save money, looking at ways that home helpers might exercise more (or even less) overall responsibility in finding solutions in the form of workable tradeoffs. Another starting point again might be the training needs of home helpers and of assistees, possibly bridging generation gaps while

building on and developing further the roles of home help assistants as mediators between municipal policies and care recipients. If home helpers were to support elderly in learning ICT use this would constitute a new way of thinking of the Home Help Service in terms of task but not so much in terms of relationships and mediation: This would build on existing relationships as well as on the idea and practice of home helpers “bringing external impulses” to home-bound people. It would also give a new impetus to the municipal IT project, allowing spreading of ICT knowledge in novel ways, developing the Home Help Service as a mediator of familiarity with ICTs (rather than the HHS being relegated to an ambiguous end point of efforts to spread ICT). A fourth starting point for ICT development projects in this realm might be the potential for a political mediation role, examining ways that home helpers might make use of ICTs e.g. to communicate concerns about assistees to them and to pass on their understanding of general issues to decision makers. The latter would link up well with the existing “IT and democracy” efforts of the municipal authorities but would require decision makers to be willing to listen to the wealth of experience of home help assistants.

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#### FOOTNOTE

<sup>1)</sup> I have been impressed that despite my infrequent visits a few assistees have even remembered me. One elderly assistee I had met several times over the years, mostly only a few minutes at the time. When visiting in December 2000, her body—as so often before—was shaking with Parkinson’s disease while she was waiting for medication to be given and to take effect. We had last met in 1998; yet, she remembered my name, details of my family, and my work as a researcher in computing. I remain deeply touched by her extraordinary memory and willingness to see me as a whole person and ours as a real relationship.

#### REFERENCES

1. Andersson, K.-E. and Ortmann, L. *Omsorg med IT på äldre da'r* [Care giving with IT in the aged years]. Available as from Telia, Sweden, as Teldok report 102, series ISSN 0281-8574.
2. Asaro, P.M. Transforming Society by Transforming Technology: The Science and Politics of Participatory Design. *Accounting, Management and Information Technologies* 10, 4 (2000), 257-290.
3. Beck, E.E. Managing Diffracted Rationalities: IT in a Home Assistance Service. In I. Moser and G.H. Aas, *Technology and Democracy: Gender, Technology and Politics in Transition? Proceedings from Workshop 4*, from conference “Technology and Democracy - Comparative Perspectives” (Oslo, January 1997). TMV Skriftserie no.29, 1997, Centre for Technology, Innovation, and Culture, Univ. of Oslo, Norway.
4. Beck, E.E. What Doesn't Fit: 'the Residual Category' as Analytic Resource. In C. Floyd, Y. Dittich, and R. Klischewski (Eds.) *Social Thinking — Software Practice*. MIT Press, Cambridge MA US, 2002.
5. Beck, E.E. P for Political: Participation is not Enough. To appear in *Scandinavian Journal of Information Systems* 14, (summer 2002).
6. Beck, E.E., Madon, S. and Sahay, S. On the Margins of Information Society: A Comparative Study. (Unpublished working paper.)
7. Bjerknes, G., and Bratteteig, T. User Participation and Democracy: A Discussion of Scandinavian Research on System Development. *Scandinavian Journal of Information Systems* 7, 1 (1995), 73-98.
8. *ERCIM News*, 48 (January 2002). [Special issue on e-government]. (Newsletter of the European Research Consortium for Informatics and Mathematics) (Entire issue)
9. Heikkilä, J., Kallio, J., Saarinen, T., Tuunainen, V.K. EC of Groceries for Elderly and Disabled: Comparison of Alternative Service Models. In N.J. Buch et al. (Eds.) Proc. of the 21<sup>st</sup> Information Systems Research seminar in Scandinavia (Sæby Søbad, Denmark, August 1998), Dept. of Computer Science, Aalborg University, pp.337-350.
10. *IDS Bulletin* 20, 2 (April 1989). [Special issue on Vulnerability]. (Institute of Development Studies, Univ. of Sussex, UK.) (Entire issue)
11. Isaksen, L.W. *Den tabubelagte kroppen: kropp, kjønn og tabuer i dagens omsorgsarbeid* [The taboo ridden body: Body, gender and taboo in today's care work]. PhD thesis 1994, available from Dept. of Sociology, University of Bergen, Norway.
12. Madon, S. and Sahay, S. An Information-Based Model of NGO-Mediation for the Empowerment of Slum Dwellers in Bangalore. *The Information Society* 18, 1 (2002), 13-19.
13. Nygaard, K., and Bergo, T.O. *Planlegging, styring og databehandling. Grunnbok for fagbevegelsen* [Planning, management and data processing. Handbook for the labor movement.] Volume I. Tiden norsk forlag,

Oslo, 1973.

14. Pihlgren, M. Biträden i uppror [Helpers revolt], *Blekinge Läns Tidning*, 8<sup>th</sup> October 1997, 10.
15. Sutter, B. *Stenbacka - Lyckseles första gruppboende för åldersdementa. Erfarenheter 1989-1992*. [Stenbacka - Lyckseles first group living trial for people with senile dementia. Experiences 1989-1992]. Available from Äldrecentrum Norr, Lycksele, Sweden: Småskrift, report 23, April 1992, series ISSN 1101-220X.
16. Svedberg, L. *Marginalitet. Ett socialt dilemma*. [Marginality. A social dilemma.] Studentlitteratur, Lund, 1995.
17. Wærness, K. The evolution of help and care needs in the context of changes in demography, values and social networks. Opening lecture at 9th Congress of the International Council of Home Help Services (ICHS), Bonn 9-14 May 1993. Occasional Papers no.120093, Dept. of Sociology, University of Bergen, Norway