

The Informatization of Welfare: Older People and the Role of Digital Services

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Abstract

The informatisation of health and social care is a central element of the modernisation of welfare. This article seeks to understand how older people have been conceptualised during the complex process of informatisation. To do this an ideal type typology is used as a heuristic and way of engaging with the complexities of informatisation and policy changes. The typology gives rise to four models that are used to highlight the dilemmas and opportunities afford by different paths to the informatisation of health and care services. It is suggested that while informatisation may have facilitated the integration of services it has been accompanied by a marginalisation of older people as users. However, it is argued that the recent transition of the Web from version one (or Web 1.0) to a significant new version (or Web 2.0) and the consequent rise of user generated information may transform the role of the user in such systems.

Keywords: computer technology, information technology, older people, service integration, SAP, social policy

Introduction

Concern about the aging population across Europe and the potential demands on state resources have made services for older people a key target for information technology initiatives and related policy interventions. This paper examines the role of older people as users in the increasingly information-led area of health and social care (the label ‘user’ is taken

Table 1 A typology of health and social service informatization

	Older user engagement low	Older user engagement high
Service integration low	Traditional practice	Experimental practice
Service integration high	Emergent practice	Future practice

to include, where applicable, carers and family members). In particular, the authors seek to situate the development of information technology in the context of the delivery of care to older people. The intention is to provide an account of past relationships between policy, practice and information technology in order to highlight emerging and future opportunities and dilemmas. To do this, it is necessary to draw on a wide range of literature and perspectives, including gerontology, human–computer interaction (HCI), e-health, psychology, sociology, social policy, social science of technology (SST) and social work. It is not proposed to review or examine any one of these approaches in detail or systematically, but rather the intention is to bring them together within a conceptual framework. This framework is shaped by two significant themes that are evident across the research and policy literature. The first theme relates to the role of the user and, in particular, those, such as older people, who are the subject of information technology interventions. Older people have been relatively neglected as users compared to other groups, partly because they have been regarded as in a minority of information technology users or on the assumption that practitioners or carers will use resources on their behalf (Newell and Gregor, 2002). However, older people are increasingly placed at the centre of information strategies. The second theme reflects how the delivery of services is shaped by the form, responsibilities and expertise of the various organizations and professionals involved in the care of older people. For example, the integration of services has transformed past divisions between health and social care. User engagement and service integration therefore provide the two dimensions of a typology that is developed in this paper to generate four ideal type models (see Table 1). These models are discussed in some detail and used to highlight past developments in order to understand the significance of recent innovations in information technology and, in particular, the role of the older user.

The promise of information technology

Computer-based information systems have a long complex relationship with governments and health and welfare services. This engagement began with various ideas about ‘electronic government’. The label ‘electronic’ has since been applied as the prefixed ‘e’ to large parts of state and commercial activity. Whether it is e-health, e-welfare or e-government,

the 'e' holds out the promise of vast data collection, storage and the performance of complex tasks quickly and reliably. To do this, information systems demand clear rules and carefully followed procedures (Parton, 2008). In other words, the process of informatization resembles much of Weber's nineteenth-century model of bureaucracy. This appeared to herald a new modern age in a way similar to more recent claims made about the possibilities of a new electronic age or information society. Utopian visions forecast the 'problem of leisure', the 'paperless' office and, following Toffler (1980), the decline of bureaucracy (Seabrook, 1988). In contrast, dystopian visions drew on Orwell (1954) and Huxley (1932), who tapped into Weber's fear of uninhibited bureaucratic domination. Here, e-government, with echoes of Adorno's model of the administered society, becomes variously the all-seeing and controlling 'computer state' or the 'surveillance society' (Burnham, 1983; Lyon, 1994). However, during the wave of informational projects undertaken across the globe in the 1970s, 1980s and 1990s, information technology was viewed as intrinsically neutral (Hand, 2005). This perspective was challenged by Glastonbury (1985) and others as the impact of such projects on the organization and practice of social work became increasingly evident (Glastonbury and LaMendola, 1992).

The introduction of information technology has often been a central part of broader attempts to reorganize state services and administration. The progressive reconfiguration of state services in the UK and elsewhere since the 1980s has been accompanied by information technology initiatives (Jessop, 1994; Savage and Atkinson, 2001; Ellison, 2006). For example, the White Papers *Working for Patients* (Department of Health, 1989a) and *Caring for People* (Department of Health, 1989b) sought to introduce consumer-centred services and choices. The move to services arranged around consumer choice does not simply arise out of a policy-level desire to achieve apparent cost saving or the fulfilment of political ideals, but also reflects a long-standing concern about the way the delivery of care may foster dependency and powerlessness (Townsend, 1981; Arber and Ginn, 1995; Walker, 1999). The citizen as consumer creates a new demand for flexible, local and responsive solutions to choices and needs (Gomm, 1993). Information technologies were seen as particularly suited to promoting the required decentralized systems that worked across geographical and organizational boundaries (Castells, 2000). Reflecting these ideas, the Department of Health launched the *Information for Social Care* initiative in 2000. However, the promise of increased efficiency and improved working practices through the introduction of new technology was not always fulfilled. Various failed information technology projects in the UK have been identified, including a costly and never-completed system for the NHS Wessex Region (Klein, 1994; Collins, 1997; Dunleavy *et al.*, 2006). Such problems informed the Wanless (2002) that highlighted

the importance of information technology and the need to allocate adequate resources and management to future interventions.

Older people at the 'centre' of informatization?

The reconfiguration of welfare services around individual responsibility and choice is one of the 'grand narratives' of social policy in the last quarter of the twentieth century in the UK and elsewhere (Moran, 2003). Terms like 'user-centred services', 'partnership' and 'empowerment' have since become common in policy documents and guidelines for practitioners (Carey, 2006; Scourfield, 2007). While the medical profession has retained—albeit with a changed meaning—the label 'patient', other professions involved with older people have, in some cases, moved from the notion of 'clients' to one of 'users' or 'service users', while still resisting the label 'customer' (Hardey, 2008; Heffernan, 2006; Scourfield, 2007). Initiatives including *Information for Social Care* (Department of Health, 2000) and *Delivering 21st Century IT Support for the NHS* (Department of Health, 2002) promoted a 'seamless' service to the older user. The Single-Assessment Process (SAP) is central to this intensification of informatization of older people's services. The emphasis on local solutions to the implementation of SAP reflects traditional national/local government divisions that have resulted in different policies, practices and technologies being used in relation to the delivery of services to older people (Powell *et al.*, 2007). Symbolizing the central role of the user, a paper copy of the care plan, derived from SAP, is kept by the older person.

The modernizing process reflects the shift from a model of user behaviour as one that can be characterized as 'deference, obedience and instruction' after Parsons' (1951, 1975) formulation of the sick role (Neuberger, 2000). How people engage with and are perceived by the services and systems they encounter is increasingly shaped by information technology. The two dimensions of service integration and user engagement have shaped, and continue to shape, the organization and delivery of care to older people. These can be mapped to produce an ideal type typology that helps to reveal the role of the user within informational processes (Table 1). The typology provides a heuristic way of engaging the complexities of informatization and policy changes (Hardey, 2009). The degree of user engagement is mapped on a high/low continuum on the horizontal axis. 'User engagement' indicates the extent to which older people are included or excluded as participants in the informatization process or as users of information systems. A high to low integration of services is represented on the vertical axis. For the purposes of the typology, 'integration' reflects the way relationships between different services, sectors and professions shape the provision of care to older people. The

mapping generates four ideal type models, which are outlined below. As an ideal type exercise, the models should be viewed with the usual caveats.

Traditional practice

This model is 'traditional' in the sense that it represents the structures and strategies that emerged when modern state-led welfare systems were developed in the wake of the Second World War. The delivery of welfare services to older people was characterized by vertical control and professional differentiation so that health and social care practitioners tended to operate in organizational and information silos (Lewis, 2002; Glendinning *et al.*, 2005). It might therefore be more appropriate to label this model as 'traditional practices' in recognition of the diversity of agencies and organizational practices that were in use before the 1980s. Given the divides between national and local responsibilities and across the health and social care sectors, the role of information technology is equally divided and diverse in this model (Rafferty, 1997). By the late 1990s, this mode of operations was viewed as dated and lacking efficiency in a 'quickly changing world' (Cabinet Office, 1999, p. 35).

Within the traditional practice, the older user was subject to separate interventions from any number of agencies and related practitioners. For example, doctors were largely disengaged from social workers and, consequently, older people would find themselves providing the same information to different practitioners and agencies. Various implementation failures and a growing recognition that information technology was not an inexpensive panacea for organization and other problems were eventually recognized (Wanless, 2002). In terms of information technology, older people are absent except as subjects about whom information is held and used. Indeed, traditional practice was established before there was a broad public engagement with information technology. It was not until the 1990s that the internet made a public impact. The focus of attention in terms of information technology was therefore organizational as new systems were being developed largely independently in different sectors (Gould, 2003). The consequent 'heritage problem' remains and helps to account for the slower than anticipated implementation of, for example, the national patient record system (Department of Health, 2002).

Experimental practice

Many pilot studies and experimental projects have developed systems to test potential information systems. These constitute 'experimental practice' because they provided the means to test how improved systems could be developed and introduced. Some projects assumed a high level of service

integration but collaboration between services and agencies was limited to the requirements of an individual project. In this respect, experimental practice is cut off from the mainstream delivery of care. By their nature, the projects are diverse and not all are aimed at the older person as the end user. However, there is common recognition of the need to consider the user and many projects draw on HCI to influence the design of information systems (Webster, 2009). The following two examples are provided to illustrate the different assumptions made about the role of users and information technology. First, the 'FrAMework for Multi-agency Environments' (FAME) project initially involved six local pilot projects in England. The project used information technology to support collaboration and interaction between practitioners through the effective exchange of information (Gannon-Leary *et al.*, 2006). In this, FAME was influenced by other back office schemes in which the emphasis was on the organization of information to facilitate the delivery of care. The integration of services was necessarily confined to demonstrator sites that may have benefited from a Hawthorne effect. However, such projects have helped to shape the informatization of health and social care as well as pointing to ways in which technology can support the integration of services. The second example takes a contrasting perspective. The 'SWIFT' project was a European demonstration of an implementation of information technology around the needs of older people (Tzamarias, 2002). A pilot site was based in Derwentside and an aim of the project was to give older users access to the SWIFT system so that they could contribute and use information. Like some other projects, user modelling or the examination of how people used the system was an important aspect. This placed the older person at the centre of an information system in which health and social care is one possible area of interest amongst other options that include e-mail and shopping.

Emergent practice

The model of 'emergent practice' reflects the current situation of health and social care. The label 'emergent' has been used in recognition of the continuing changes that are experienced at all levels. As noted previously, the heritage of past technology systems and organizational differences shapes the implementation of new strategies. Services are increasingly integrated and information technology systems are increasingly shared by health and social care practitioners who have access to more or less integrated databases (Department of Health, 2002). However, regional, professional and organizational divisions remain and, at the level of users' information, there is a debate about the degree to which information should be shared across such divisions (Richardson and Asthana, 2006). Consequently, the integration of services and information technology remains an aspiration

rather than reality in many places. This model also reflects the way that institutional-led information system ‘users’ are currently not conceived of in terms of the older person or service user. Despite various information-led pilot or demonstrator systems, the speed with which SAP and other procedures have been introduced nationally means that there was limited opportunity for refinement. Indeed, social workers and others delivering front line services have also indicated that they have not been adequately consulted as users within the informatization processes (Challis *et al.*, 2006; Dickinson, 2006). In terms of implementing information systems, there remains limited time to train those who had to build their working practices around new procedures and technologies (Keeble *et al.*, 2009). To put it starkly, older people remain represented as subjects of informatization, as practitioners largely mediate their information needs. In this sense, older people remain a source of data rather than as partners in the creation and management of both their data and the way it is used by practitioners and organizations.

Future practice

This model offers a chance to use the trends noted previously to attempt to understand how health and social care will develop in the light of informatization and policy changes. ‘Future practice’ represents the fulfilment of the policy ideal of integrated care services and ‘joined up’ government at both local and national levels (cf. Bakker, 2002). This suggests an information system that is capable of providing reliable and seamless information at the point of use to users that may include older people. SAP negotiation can be virtual, as initial assessments may be conducted with the aid of eSAP and a laptop that interacts with a ‘Spine’ (Mouratidis, 2003). *Connecting for Health’s* notion of a Spine allows health care and other records to be accessed remotely. Subsequent changes may be made through eSAP and the older person should be able to initiate such changes themselves. The functionality envisaged by the FAME and SWIFT projects has shaped a system in which information is passed seamlessly to and from older people, practitioners and others involved in delivering care through a common interface.

Behind this model of future practice lurks the notion of the properly informed, flexible user who is expected to make choices from a range of public and private provisions. Direct payments may be the harbinger of the older person as a ‘responsible’ and ‘empowered’ consumer who is expected to be self-vigilant and self-managing (Rose and Miller, 2008; Department of Health, 2001). The continued consumerist reorientation of public services appears inescapable so that choices and risks will become increasingly individualized (Bauman, 2001; Beck and Beck-Gernsheim, 2002). However, technologies are increasingly vigilant on behalf of users. For example, telecare

technologies may reduce reliance on human agency through bodily monitoring systems. A fully integrated telecare and information system can embody users so that their needs may be met before they themselves may be aware of them (Audit Commission, 2004). There is a congruence here with 'software-sorting' techniques whereby data from diverse sources are used to provide services to people according to their social and economic standing (Graham, 2004). Transferred to the domain of social care, there is the potential to generate a digital 'undeserving' or otherwise less privileged group of users. Concerns about surveillance and state power are also important if users are recast as subjects of 'datavallence' so that while their needs might be met, their choices could be prescribed, as they are socially sorted in order to provide an 'optimal' delivery of care (Lyon, 2003). Some form of digital inequality will persist and it is possible that those who demand purely face-to-face interactions will receive a residual service due the comparatively high costs of the service. There is also potential for creating a new category of 'system outcasts' who may be victims of data errors or, through data processing, found not to be entitled to citizenship rights.

The future practice model raises the question of how far the informatization of care should go in addressing the needs of users. It is not difficult to envisage a system that, while, in theory, empowering older people through their computer that is located in their 'smart home', may actually reduce face-to-face contact with others, discourage mobility and generally adversely shape their well-being.

A version change?

This paper has reflected the 'top-down' and institutional nature of informatization and the large projects that are involved in delivering information services to practitioners and others. This mode of thinking is now challenged by the recent transition from version one of the Web (or Web 1.0) to a significant new version (or Web 2.0). Academic and popular commentaries about Web 2.0 identify new modes of engagement and interaction, which transform the way information is created and used (Hardey, 2007; Tapscott and Williams, 2006; Beer and Burrows, 2007). A range of new resources is now available that are global in extent and centred on user-generated data. There are three pertinent examples. First, initially launched in the USA, a number of websites allow users to search for and view details about doctors and other health professionals. For example, RateMD.com (www.ratemds.com) allows users to rate on a four-point scale named practitioners. In addition, they can also leave a text-based account of their experiences with a particular practitioner that can be read by any other user. Although the site is based in California, there are a growing number of reviews of doctors working in Canada, the UK, Australia and New Zealand. Similar user review sites have been launched in Germany, such

as Jameda.de (www.jameda.de) and Checkthedoc.de (www.checkthedoc.de). A site named IWantGreatCare (www.iwantgreatcare.org) has recently been launched in the UK. Within the complex market-led care system in the USA, citizens are cast in the role of consumers, who must navigate and make choices about services. Internet-based sites have therefore provided information about services in a more commercial fashion than in Europe and other countries with state-led universal health provision. However, it should be noted that many less privileged people in the USA have a highly constrained choice of health and welfare services and provision. The second example is represented by a site called Patient Opinion, launched in 2005, that allows users to rate, write and view comments about the health care they have received from identified units but not named practitioners. For example, it is possible to search for and read/write comments about an identified hospital ward. Significantly, the site has agreed to share or 'mashup' information with the NHS Choices website (www.nhs.uk/Pages/homepage.aspx). Comments by users can also be sent directly to quality managers concerned with a particular institution.

These user review sites are still 'young' but their potential popularity can be gauged by the more established commercial user-generated review sites. For example, TripAdvisor (www.tripadvisor.com) lists hotels and other travel and holiday information. It has millions of users from across the globe and it has been reported that 40 per cent of internet users make purchases based on information from user review sites (Eikermann *et al.*, 2007). It is easy to object that such sites are not relevant to the delivery of services to older people. However, older people have been shown to adopt technology when they perceive it useful to them and the 'silver surfer' label confirms this (Selwyn *et al.*, 2003). Future generations of older people will be more familiar with information technology and will expect to use it. It requires only a small imaginative leap to envisage a role for a user review site called MySocialCare that will allow people to rate and comment on social workers and other practitioners.

The final example was again first developed in the USA. Google has devised a 'personal health record' into which users can copy their health details and other information. Each user is given a 'unique url' so that authorized users (i.e. those identified by the user) can access the data. In effect, Google has rolled out a patient record system resembling that being developed by Connecting for Health (www.connectingforhealth.nhs.uk/). However, the approach is different in that user-generated data drive the system. Although it is too early to assess the role and impact of the resource, the Google record is already being combined with the services provided by some health care organizations in North America. The system is proving attractive for older people who travel because it gives them a portable health record should they require health care. What connects these Web 2.0 developments is that they are outside any one national system of care and are only useful if users provide information to them. The suggestion

here is that informatization may be taking a user-led turn. Institutions and policy makers have largely succeeded in establishing information technology for organizational purposes at the expense of marginalizing the role of the older person as a user. The question now is how do institutions and practitioners respond to and make use of user-led informatization?

Conclusion

A motive for writing this paper was a wish to recognize how informatization within health and social care has perceived the older user. The typology that has been presented is part of an attempt to understand the complex history and development of services for older people that are undergoing a continued process of informatization and change. It is argued that policy and practice innovations over the decades have variously changed the conceptualization of the role of the older person from one akin to that of a patient to a role closer to that of service user or customer. Such changes represent more than policy rhetoric, as they reflect and shape the way services are organized and the degree of labour that older people need to invest in them in order to take advantage of choices that are available. They also reflect changes in how care is delivered and tie into policy that advocates an increasing role for the voluntary and commercial sectors. The 'electronic fix' has transformed how care is provided to older people. However, in achieving increasing levels of service integration and informatization, the older person as a *participant* in the system has been marginalized. If policy and government statements in the UK and elsewhere are to be taken seriously, the older person should be seen as the 'responsible' and 'empowered' consumer. The website NHS Choice is indicative of such trends. Few older people currently using health and social services may be these informed, empowered, articulate and demanding citizens. Indeed, such characteristics may reflect a middle-class and de-politicized 'entrepreneurial self' that seeks to maximize individual choices and well-being (Petersen and Lupton, 1996). However, this ignores family members and carers who may be acting in this manner. Future generations of older people are already contributing to user review sites and the NHS has already sought to incorporate some aspects of these into institutional quality control systems. While it is too early to be sure about the likely role and impact of Web 2.0 on health and social care, it is clear that it will change how people use services and engage with practitioners. This marks a shift in informational development that may be moving away from an institutional perspective to one in which innovations develop outside organizations and situate older people as *active* agents in the system.

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