

Results of the study

# »Ethical questions in the area of age appropriate assisting systems«

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### **IMPRINT**

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# Technological change and serious moral questions

Technology has become a companion to our everyday lives. It has vastly increased the number of things we are able to do and has helped to alleviate difficulties great and small. At the same time we experience technology as a part of certain problems which evidently cannot be solved using it. Human beings and technology are in a tense interrelationship in which the former create the latter and use it to shape the world and shape themselves, but at the same time technology also shapes people in the way they perceive themselves and the world and in the way they judge and act. The advancement of science and technology forces individuals and society as a whole to endure ever-increasing levels of change. This is not only an intellectual, physical and mental challenge, it is a moral one. The serious moral questions that it entails force us to examine the very foundations of our existence: 'The way we answer these questions decides who we are, what kind of people we are, and in which society we live.' (Böhme 1997: 17).

The use of age appropriate assisting systems poses this kind of serious moral question: how can we serve elderly people in their neediness and help them to live lives on their own? Theirs are lives that perhaps involve frailness, but most certainly involve mortality. Lives that want to be lived with the greatest possible individuality and freedom. We may therefore ask: what are the political, moral and economic resources which society delivers to support elderly people? Whether and to what extent this support is provided in technical form is a question not only of the moral and political obligations that are binding upon a society, but also of the technical nature of the support: how does technology change the fabric of society and the cohesive forces within it? This brochure provides a summary of the accompanying study entitled 'Ethical aspects in the area of age appropriate assisting systems' which was initiated by the German Federal Ministry of Education and Research (BMBF) in 2012 as part of the funding project

'Age appropriate assisting systems for a healthy and independent life'. It aims to inform those who are interested and those who are affected, it aims to help the necessary questions to be asked in appropriate places at the right time and for them to be tackled constructively. It offers information and a toolset with which to identify problems arising in a structured way and make responsible decisions about them within their contexts.

### 1. Ethics as a means of tackling serious moral questionsaims and structure of the accompanying study

An ethical evaluation of age appropriate assisting systems involves broaching 'serious moral questions' (Böhme 1997). On the one hand this means describing the social and technical preconditions that lead to the development and potential use of such systems. On the other hand there is the important business of predicting any unwanted consequences which a given technology may bring, which one then attempts to avoid by designing the technology appropriately. With the toolset it contains, the study provides an approach to tackling prognosis and technological design. It ought of course to be borne in mind that the toolset we have provided has to be evolved in line with technical transformation and social changes-in other words it requires dynamic ongoing evolution.

Because prognosis is in principle difficult, ethical evaluation faces the challenge of presenting its arguments in a substantially clean and comprehensible manner. This means that serious moral questions have to be formulated and expanded upon in such a way that, confronted by the potential consequences of technical development, we do not invoke scenarios that immediately condemn any further development as questionable. On the other hand ethics ought not to automatically endorse socio-technical change without substantiated reflection.

Generally speaking, modern technology is a complex configuration of machinery, processes and players. The resulting joint actions are based on a division of labour which entails a division of responsibility. It is however important that this does not lead to a 'diluting of responsibility' (Hastedt 1991) or most especially to 'organised irresponsibility' (Beck 1988). In ethics, responsibility is a powerful element when reflecting on action (and inaction), which is why ethics insists that those who bear responsibility remain identifiable (Manzeschke 2011). With technology comes the claim that it ought to be available 'for all'. It is however designed by experts. From an ethical point of view it is important to ensure that technology is developed not only for but also with the target group—and that most certainly applies to age appropriate assisting systems.

Furthermore it should be noted that even the development of certain technical systems entails a moral decision while their implementation dictates structures of considerable duration and either excludes revisions and alternatives or only permits them in a path-dependent way (cf. Winner 1980). Associated with that is a problem which has appeared in academic discussions named Collingridge dilemma. This states that the potential consequences of a technical development are difficult to foresee, and therefore may only be controlled and guided to a very limited extent. And, by the time a technology is established, its structures are so deeply rooted that it is virtually impossible to change or undo them (cf. Collingridge 1980).

# Aims and results of the present ethical study

The aims of the ten-month accompanying study (January until October 2012) were

- to identify the key ethical problems in the use of age appropriate assisting systems and to do so using ongoing funding projects, empirical investigations and theoretical studies,
- to provide players in the field (research and development, suppliers and users) with an ethical toolset which enables them to identify ethical problems and tackle them constructively,
- to formulate guidelines providing ethical orientation for public and private work in the field. The study also provides:

- a critical review of key ethical tipping points and areas of conflict that can arise when using age appropriate assisting systems and which should therefore be considered early on. This then connects to:
- an outlook on further research that is required.

The brochure contains six main articles describing the fundamentals of the study's methods and results. For a complete insight, especially into the methods and literature used, please refer to the accompanying study (Manzeschke et al. 2013, in German only).

Following some basic discussion of ethics and the way technology is evaluated and formed, the first chapter provides an overview of the study's aims and structure.

The second chapter picks up on the terms ambient assisted living and age appropriate assisting systems, sketching their specific characteristics along with real and potential ethical problems that can arise from their use.

The third chapter examines the political, cultural, legal and economic contexts in which these systems are or will be used. Looking beyond demographic change, this section portrays structural conditions that need to be considered in their interdependence and path-dependences if the use of age appropriate assisting systems is to be justified theoretically and exercised successfully.

The fourth chapter introduces the ethical evaluation instrument MEESTAR which was developed during the study. The acronym stands for Model for the Ethical Evaluation of Socio-technical Arrangements. The model represents a three-dimensional evaluation instrument which, in a structured fashion, instructs its users on how to reflect ethically and form judgements on the use of age appropriate assisting systems. It is also a heuristic instrument applied within a structured dialogue (ideally in workshops) based on an actual socio-technical scenario to analyse its application and, on the basis of any moral problems identified, develop solutions pertaining to its use.

The fifth chapter introduces the ethical guidelines which were drawn up over the course of the study as a result of theoretical considerations on the one hand and empirical validation during expert interviews and focus groups on the other. These guidelines document a work in progress and are open to critical comment and further development.

The sixth chapter takes a closer look at what we refer to as 'ethical tipping points' and those areas of conflict that emerged during the study as morally sensitive and that therefore need to be looked at carefully. These are, firstly, changes over time in socio-technical arrangements which can cause beneficial, helpful assistance to tip over into problematic, burdensome assistance. Secondly they involve conflicts of aims and dilemmas which cannot be resolved easily or in general terms.

Finally the brochure offers a summary and a look ahead to future research issues which arose over the course of this study.

# 2. Age appropriate assisting systems-a pragmatic approach

In Germany (and Europe), age-appropriate assisting systems are often associated with the term ambient assisted living (AAL). This refers to a broad stream of technological concepts such as ambient intelligence, ubiquitous computing and pervasive computing; these are technologies that aim to supply information- and communication-oriented services without their equipment being recognisable as technical artefacts. The idea is to equip and interweave the environment itself with technical functionality (cf. Weber et al. 2009; Weber 2012) and to open up users' environments to them by means of information (cf. Wiegerling 2012). Marc Weiser expounded this idea right back in 1991 in his essay 'The Computer for the Twenty-First Century':

'The most profound technologies are those that disappear. They weave themselves into the fabric of everyday life until they are indistinguishable from it.' (Weiser 1991: 94)

Systems supported by information and communication technology have been developing rapidly for a long time in medicine and care. Such systems play an important role in an increasing number of areas, especially where there are no suitably trained personnel to provide care nearby (cf. Flesche, Jalowy, Inselmann 2004). Applications range from advising patients who have limited or no access to medical or nursing staff, to technical support services aimed at sustaining physical and mental faculties, all the way to computer and robot assisted operations in which the doctor and patient are a long way apart (e.g. Merrell 2005; Satava 2005). Emergency medical care (e.g. Skorning et al. 2011) and accident prevention (cf. Leis 2008) are other areas in which such systems are becoming increasingly significant. It is difficult to tell many of these cases apart from telemonitoring as a means of monitoring vital statistics (refer to Meystre 2005 for an overview). The term eHealth is often

used as a collective expression of the numerous concepts and areas of application for information and communication technology in the healthcare sector (cf. Oh et al. 2005; Jähn, Nagel 2004).

We cannot pursue all of these numerous approaches here. What we do intend to indicate though is that the development of age appropriate assisting systems is taking place across a broad field in which boundaries cannot always be clearly drawn between technologies, target groups and areas of application. In this study we have concentrated on applications developed and made available primarily for elderly people so that they can use them to live autonomously in their own households for longer. To do this we use the BMBF's definition of ambient assisted living:

'The term ambient assisted living (AAL) refers to concepts, products and services that connect new technologies and social settings to each other, mutually improving them with the aim of raising the quality of life of people in every phase of life – but especially in old age. The best translation of AAL might be age appropriate assisting systems for a healthy and independent life. This already indicates that AAL primarily involves the individual in his or her direct environment.'

### (AAL Deutschland)

In this definition healthy life indicates the institutions and procedures of healthcare; independent life can be taken as a reference to the key socio-political terms of autonomy and social participation. To put this definition into practice, technical assistance systems are employed in particular in the living environment of elderly people. Age appropriate assisting systems should therefore not be understood or assessed as purely technical artefacts, but instead as socio-technical arrangements with potentially farreaching consequences for the individual and society. Age appropriate assisting systems are understood as socio-technical arrangements because of the fact that they support people in two ways: firstly, elderly people use these systems themselves with the aim of experiencing an improvement in the quality of their lives within their day-to-day contexts. Secondly these systems are intended to assist relatives and healthcare/nursing staff to take care of elderly people.

In many cases age appropriate assisting systems are based on the idea of an invisible, ubiquitous, efficient and far-reaching kind of information and communication technology. Since users may well be limited in their sensorimotor possibilities, manmachine interaction is not limited to inputting and receiving information via a screen and keyboard but takes place instead in multimodal channels that perform and enable intelligent, often fully automated interactions. The technologies involved become background technologies, ones which may well be impossible to keep full track of in their overall consequences and scope of their features.

Assisting systems aim to support old people in their households environments, this being also a symbolic place—wherever a person is at home (cf. Betz et al. 2010a: 58f.). So when an assisting system is used, a person's home may not be viewed merely as accommodation which requires technical equipment. Instead it is considered primarily as a living-space and as a meeting-point of social relationships and a locus of those memories that make up the person (Manzeschke 2010).

### 3. Structural surrounding conditions-assisting systems and their social context

In the social sciences they speak of the population aging in three respects: elderly people in the population are becoming more numerous in relative and absolute terms, and are attaining ever-older ages (cf. Weber, Haug 2005). As desirable as that may be it also means a rising demand for medical and nursing care that needs to be met financially and organisationally. Depner et al. (2010: 33) state 'that there is a growing proportion of people who need care and live aloneand who can rely at home on only a precarious care network, if any'. In this context it should be noted that the legislature has itself prescribed the more cost-effective mode of care in § 3 SGB XI (German Social Act) (for further reading see Gerhard 2010; Bleses 2009; Cappell 2005). The out-patient before in-patient principle contained therein also envisages strengthening informal helper structures. What is known as the civil society-consisting of retired persons, neighbours, friends, and charitable organisations-is envisaged as helping relatives to care for old people at home. At the moment, most of the people considered in need of care as defined in SGB XI are looked after by relatives in receipt of an attendance allowance (Federal Statistical Office 2011).

This entails a structural dilemma which Sabine Bartholomeyczik (2010: 141) has described as the 'Janus-faced nature of care'. What she means is that the introduction of social care insurance in 1997 placed care for the first time as a professional activity alongside the services of medical doctors—and no longer beneath them. At the same time this law is based upon an idea of care whereby it can basically be provided by anybody, especially relatives without professional training. In this way of looking at things it is primarily the relatives who provide the care, and professional carers are called in only if there is too much to do, not for their expertise.

In this situation, age appropriate assisting systems aim to help ensure that a) older people can live longer at home, b) their relatives and neighbours are helped in the assistance they give them, and c) the cost of care is reduced or at least kept stable.

# Financing age appropriate assisting systems

It is still not yet exactly clear how the new age appropriate assisting systems are to be financed (cf. Gast 2013). The current structure of care at home (care provided on the one hand by professional carers and on the other by unofficial, private care networks) makes it almost impossible to quantify the actual costs of these care arrangements. Macro-economic calculations contrast the high costs of formal nursing staff against the cost of care using technology. Aside from the question of whether and which areas of care can be substituted technically, there is still no evidence of the cost-efficiency of technical systems. The market potential of such systems has been examined in the economic accompanying study. Willingness to pay among potential users of age appropriate assisting systems is put forward as a considerable barrier to quick market entry. It is said that there is a lack of business models containing workable financing concepts (Fachinger et al. 2012: 42f.). Because health and care insurance companies are currently very reluctant about approving finance, according to the study it is to be expected that these products will at first be financed exclusively privately and that their inclusion in the catalogue of services covered by health and care insurance companies will only be considered once there is evidence of economic or health benefits (ibid.: 51).

It is still unclear how this financing gap will be filled. From an ethical point of view we need to ask how members of society will be provided with care which fulfils their political rights and moral demands. This is above all a question of justice. The government has to create the surrounding conditions that will enable an equal, just and human treatment of the sick (§ 70 SGB V).

### **Changes in privacy**

The technical nature of many assisting systems poses a series of legal questions which in turn lead into ethical realms such as privacy and justice. In its evaluation of such systems, the legal accompanying research on age appropriate assisting systems pointed out that many of these systems enable the collection and evaluation-and passing-on-of sensitive health-related data (ULD 2010: 54). This often automated process has some critical characteristics that need to be examined ethically beyond their mere legal dimension. Ambient data processing deprives users of an increasing level of insight into and influence over the data surrounding them and associated with them. People who are cognitively impaired because they are suffering from dementia may well run up against the limits of their informational autonomy. Cases of a limited or non-existent ability to give approval to something may well be resolved through legal representation, but it ought to be borne in mind that the need for informed consent by users or their legally appointed representatives has to exist before the systems are used. Secondly we need to ask whether this precondition, which is significant from the point of view of liability law as well, can be fulfilled (ibid.: 4). In such cases the ability to remain in one's household environment is purchased in exchange for a loss of privacy, which should also be understood as a restriction of autonomy. But then again, remaining in a household environment (as opposed to entering a care home) can be considered a higher form of autonomy in the way one leads one's daily life. Similar postponements can already be seen in normal care provided by personal carers, even if the quantity and quality of data collected by

a carer are different. This brief examination makes it very clear how difficult and complex the changes brought about by a technically assisted care arrangement are in terms of the way these people live their lives and see themselves (cf. Manzeschke, Oehmichen 2010).

### Mobility in old age

Family situations in households are undergoing change. It is predicted that the number of single households (both young and old people) will continue to rise-with consequences for care (cf. Depner et al. 2010: 13ff.), although it is worth mentioning regional differences and a disparity between town and country. Social mobility patterns are also changing (e.g. through training and careers). Older people exhibit different mobility behaviour from younger people. Most of their movements take place within a radius of between one and three kilometres (cf. Depner et al. 2010: 18f.). In rural areas a restricted radius of movement can impact negatively on the accessibility of care facilities and on quality of life. This implies that in rural areas especially, mobility support for older people is key in helping them to live autonomously and participate effectively in society (cf. Betz et al. 2010a: 48).

### User involvement and user acceptance

Technology is supposed to adapt itself to users and their particular needs—not the other way around. That applies especially to older people who otherwise can become overwhelmed by new (technical) artefacts, from whose benefits they are then excluded. This would suggest a participatory design of technology which integrates not only those immediately affected but also those involved within care networks (cf. Wagner 2010). The accompanying study 'User-dependent innovation barriers' also confirms that technological participatory design is essential (cf. Friesdorf et al. 2011: 5). The AAL examined show, according to this survey, little or no adaptation to the needs of older users. 'Development [...] has so far been strongly technology-driven' (Friesdorf et al. 2011: 3). For age appropriate assisting systems to be successfully introduced and employed, it is in the end important that they can still be used and understood at an advanced age—without functional breakdowns, faults or other complications. Aspects like durability and system performance may be mentioned as examples of success factors. It is important to note that user groups are highly heterogeneous (cf. Betz et al. 2010b: 102).

### **Changing expectations**

Advances in medical technology, the attributed and increasing autonomy of people who are learning to take care of their own health, and an ethical sensitivity engendered by academic and professional discussion in the field of healthcare—all these things are causing a rise in society's expectations of good care (cf. Depner et al. 2010: 33f.). It is however still unclear how these rising expectations will be satisfied, and especially how they will be paid for. These circumstances could have a significant social effect, one often noted in discussions, which is that those who have the intellectual capital to look after themselves in matters of health are generally those who have the financial capital needed to purchase the necessary healthcare services-and vice versa (Behrens 2008). As long as age appropriate assisting systems continue to be organised through a co-payer or selfpayer market, we can expect people with little capital (social, economic and intellectual) not to participate sufficiently in this care (cf. Bauer, Büscher 2008). From an ethical point of view this poses questions of justice.

# 4. MEESTAR: a model for the ethical evaluation of socio-technical arrangements

Investigating and evaluating ethical issues in the area of age appropriate assisting systems is one of the key concerns of this study. The first aspect of this is to identify and describe the ethical dimensions of a particular application scenario. This always relates to an actual socio-technical arrangement: an actual person in his or her actual social setting has an actual need for assistance which is met through a combination of personal and technical arrangements. The way this socio-technical arrangement is evaluated depends on the outlook of the evaluator: a user will perceive and judge things quite differently from somebody supplying or developing an assistance system. The fact that judgements are dependent on outlook in this way should thus be disclosed, and it is important to ensure that the various points of view are taken into account in the evaluation process.

In this chapter we will present MEESTAR as an analytical instrument (see Fig. 1) which guides the process of reflecting on the use of technology. This Model for the Ethical Evaluation of Socio-Technical Arrangements helps in a structured way to identify ethically problematic effects and, on that basis, develop ways of resolving them. Accordingly, negative effects are what the instrument focuses on because the minimum ethical requirement is that age appropriate assisting systems incur either little or no harm. If it is little then this may only go ahead with the consent of those affected, and should arise from a consideration of harm and benefit in which the harm is accepted because it is outweighed by the benefit. The MEESTAR instrument therefore only exhibits one neutral and three negative levels, but no positive one. In this way it safeguards the use of systems in a downwards direction; MEESTAR does not aim to directly offset the positive effects of age appropriate assisting systems, nor should it.

Working with MEESTAR (ideally in the form of interdisciplinary workshops) involves the systematic consideration of three axes. Along the x-axis are seven ethical dimensions (care, autonomy, safety, justice, privacy, participation and self-conception) which were identified as essential during the study. Along the y-axis, problems are allocated among four levels of ethical sensitivity. The z-axis provides three points of view (individual, organisational, social).

The key questions when using MEESTAR are:

- Is the use of a given age appropriate assisting system ethically doubtful or is it harmless?
- Which specific ethical challenges arise from the use of one or more age appropriate assisting systems?
- Can those ethical problems that arise from the use of age appropriate assisting systems be mitigated or even resolved altogether? If so, what are the potential ways of resolving them?
- Are there certain elements in the use of an age appropriate assisting system which are ethically so dubious that the whole system should not be installed or used at all?
- When a system is being used, do new and unexpected ethical problems arise which were unforeseeable when planning and designing the system?
- What are the aspects and functions of a given age appropriate assisting system which need special attention from an ethical point of view?

# The seven evaluation dimensions of the model (x-axis)

The seven evaluation dimensions are designed to enable the evaluator to identify and allocate one or more ethical issues in an actual scenario. The evaluation dimensions which have been derived firstly from the results of theoretical ethical work and secondly from a series of qualitative interviews are structured to provide the ethical evaluation with themes and content that encourage a range of considerations for discussion which are key to the appropriate application of age appropriate assisting systems. These seven dimensions are: care, autonomy, safety, justice, privacy, participation and self-conception. We will now provide a brief overview of each of the seven dimensions and delineate them by providing a list of key questions.

# Stage II: Its use is ethically sensitive but this can in practice be compensated for Stage III: Its use is ethically sensitive but this can in practice be compensated for Stage III: Its use is ethically extremely sensitive and requires either permanent monitoring or its introduction should be questioned Stage IV: Its use should be opposed from an ethical viewpoint

#### Figure 1:

MEESTAR: x-axis: dimensions of ethical evaluation; y-axis: stages of ethical evaluation; z-axis: levels of ethical evaluation.

#### CARE

The term caregiving (German: Fürsorge) is associated first of all with the Christian tradition of compassion (cf. Bayer 1998) in which people have been caring for the needy for a long time. But this is not always as altruistic as it seems—helper's syndrome (cf. Schmidbauer 1977) is rooted in that mentality. Care is sometimes connected to a paternalism which certainly does not respect the autonomy of the needy, but rather knows what is good for them (cf. Neumann 2006).

Furthermore, the English word care has established itself in the usage of other languages, including German (cf. Conradi 2001; Schnabl 2005); this came about via feminist ethics and its associated ethics of care.

Care is given and decisions and responsibility are taken on behalf of the other – the one in need – to the extent that that person is no longer able to do these things themselves – 'not to turn away from someone in need', as Carol Gilligan (1995: 32) so meaningfully put it. It is the kind of care which augments the autonomy of the needy rather than countering it. It involves a personal approach as well as interpersonal relations. And yet care of this kind can be assisted technically; this follows from the theoretical insight that technology has always expanded the possibilities of human action. Furthermore, certain people in certain situations with certain requirements may prefer technological assistance over personal support – as is most clearly the case in situations involving shame.

Ethically relevant questions in the dimension of care are:

 At which point does technically assisted care for needy people become problematic because it changes their relationship with themselves and with the world in a way they do not want, or in a way which we should not want for them?

• What degree of dependency in care structures is still acceptable or desirable, and at which point does a well-intended caregivng attitude become a patronising or negatively paternalistic approach which, under certain circumstances, might be technically supported or brought about?

### AUTONOMY

The term autonomy in the morally substantial sense basically originates in the ethical debates of the 18th and 19th centuries, from which it has found its way into everyday usage; it is nowadays often equated with an individual's maximum freedom of decision and action. Furthermore, this term, as one of four bioethical principles, has had an inseminating effect on ethical and political discourse in the field of healthcare (cf. Beauchamp, Childress 2009). A third factor is the socio-political discourse concerning the integration and inclusion of people with disabilities to which the terms autonomy and social participation have become central. A major part in this has been played by the International Convention on the Rights of Persons with Disabilities. Discussions in English do not always differentiate clearly between autonomy and self-determination (cf. Agich 1993, esp.: 7ff.), and this has in turn impacted on discussions in German as a result of translations (cf. Quante 2010). At the same time autonomy enjoys a high status in Germany, derived as it is from the inalienable dignity of the individual (Art. 1 Grundgesetz or Basic Law) (cf. also Art. 1 SGB IX, on which Dau 2009: 47, rct. 9).

Ethically relevant questions in the dimension of autonomy are:

- How can people be assisted in their autonomy on the basis of practices oriented consistently around the individual's right to autonomy?
- How can people be supported in their autonomy when their usual criteria of autonomous decision-making and action have become questionable or even untenable?
- How do we deal with the fact that ascribing autonomy can conflict with the right to care and support?

### SAFETY

Safety (also in the sense of security) is used in expressions such as sense of safety, social security, operating security, security against attack and data security. These usages encompass a very broad range of meanings yet do not possess any one discrete core (cf. Glaeßner 2002). Despite this terminological blurring, increasing safety or security is an important aim in using age appropriate assisting systems. Because these systems are designed to improve and assist a patient's life, welfare and health (cf. Schäufele et al. 2012), saftey primarily means protecting the patient against harm. Harm can happen in different ways: patients can on account of their illness find themselves in an emergency health situation which requires the medical care system to respond as quickly as possible. Increasing security means automatically triggering an alarm and initiating the appropriate assistance. In this instance saftety means providing care as quickly as possible, beyond the abilities of the occupant. At the same time, age appropriate assisting systems aim to enable people to remain within their own four walls despite their need for help and care. If we consider the home or household to be a more or less complex socio-technical arrangement, then security in such cases means increasing operational security. Domestic equipment and systems should be designed and controlled in such a way

that misoperation, technical breakdown or a combination of the two does not endanger occupants. In both cases it is not just about an objective increase in security, it is about increasing the subjective sense of safety among those affected. The feeling of security among caregivers also needs to be considered since this will presumably affect their willingness to use technical assistance systems.

Ethically relevant questions in the dimension of safety are:

- How can we counter the fact that establishing safety can sometimes reduce existing capabilities? In other words, when people begin to rely on technology they may stop taking care of certain things themselves in a productive sense.
- How should we evaluate technical assistance which increases the subjective feeling of safety without increasing safety objectively?
- How do we resolve conflicts between safety and privacy and between safety and autonomy (freedom)?

### PRIVACY

Much of the philosophical, social, and cultural academic literature deals with the issue of privacy from a point of view which has little or nothing to do with the handling of data and information. Privacy aims to establish an inviolable zone around people (e. g. Volkman 2003) and falls within the realm of negative freedoms and the right to defend (see Berlin 2002). Such rights and freedoms aim to guarantee that people can behave and develop life-plans the way they want to and without coercion, provided this does not collide with the rights and freedoms of others. Privacy is thus a guarantee of individual freedom and autonomy (e. g. Cooke 1999). Handling personal data is only one

aspect among many: Pedersen (1997; 1999) speaks of types of privacy and includes solitude, isolation, anonymity, intimacy with friends and family; furthermore, he names various psychological functions which are fulfilled through privacy: autonomy, confiding, contemplation, rejuvenation and creativity. Control over the flow of data and information may well play a role in these categories, but it is quite clear that it cannot satisfy all of the various types and functions of privacy. The (Western) concept of privacy is much older than our ability to process large amounts of data-it originates in the civil emancipation and liberal thinking of the 17th to 19th century (cf. Gobetti 1997). It should however be noted that the dividing line between public and private realms is not always there in every culture-and it can be treated differently, and therefore different behavioural patterns can exist

(e.g. Nakada, Tamura 2005; Whitman 2004).

Age appropriate assisting systems aim to provide services that are as inconspicuous and invisible as possible; they are also almost always based on the collection, processing and evaluation of sensitive personal data. Both of these aspects together can conflict with the key moral requirement of informed consent. The potentially normalising effect associated with their function can also eradicate the gains in autonomy hoped for when using this kind of system, especially with regard to privacy.

Ethically relevant questions in the dimension of privacy are:

- How can the privacy of the individual over and above informational autonomy be upheld as a moral right when designing age appropriate assisting systems?
- How can we protect the privacy of cognitively impaired people?

 How do we deal with cultural differences when evaluating private and public spheres – such as when introducing age appropriate assisting systems among people with a migration background?

### JUSTICE

Especially important in the dimension of justice is social justice. The questions surrounding access to age appropriate assisting systems need to be considered on an individual, organisational and social level. We can distinguish between at least three models describing how burdens are distributed in a healthcare system. First there is the market or libertarian model based exclusively on market-compliant processes (e.g. Engelhardt 1996) in which health services are financed entirely by those who need them. Those who need healthcare have to decide for themselves what resources they are prepared to commit and which services they will actually purchase in line with their own preferences. If particular health risks are not covered by a private insurance policy, then policyholders will not receive benefits for those particular illnesses. The pure market model is not a solidary one and based upon the performance principle.

The liberal-egalitarian healthcare model, however, aims to guarantee that disadvantages in access to healthcare services which are not the fault of those who suffer from them are compensated by a solidary insurance system (cf. Buchanan 1985; Daniels 1985). This means, for instance, that congenital illnesses and disabilities are compensated to the extent that sufferers can live autonomously. Funds must be made available collectively so that those members of society who do not have the necessary income can still receive adequate healthcare. The principle of justice is guided by neediness. Communitarian models of healthcare share the aim of distributing basic social services and assets justly but they connect this with stipulations on what actually constitutes good. From a communitarian point of view, certain ways of living are preferable to others which is why those ways have to be actively supported by the community. In this point of view, state institutions are obliged to intervene in a guiding manner. Ezekiel J. Emanuel (1998) can be considered an example of a communitarian attitude towards the healthcare system. This is an instance of a normatively conditioned justice principle of neediness.

In addition to intragenerational justice, issues of intergenerational justice must be addressed. It is feared (cf. Weber, Haug 2005) that as a consequence of demographic change, younger generations will suffer increasing economic burdens unless the size and structure of the population stabilises (cf. Bleses 2009). This is an acid test for the legitimacy of a health and care system financed in a solidary way because age appropriate assisting systems can incur considerable additional costs in such a system. If the provision of age appropriate assisting systems is cordoned off into a second healthcare market in order to avoid burdening the younger generations, access to such systems will no longer be free of discrimination unless other political steps are taken.

Ethically relevant questions in the dimension of justice are:

- Who gets access to age appropriate assisting systems?
- How should age appropriate assisting systems be financed (who pays how much)?
- What is our understanding of intragenerational and intergenerational justice?

### PARTICIPATION

Participation<sup>1</sup> in the modern welfare state means providing people with access, rights, services and assets that enable them to live together with other people in society. Excluding somebody from these rights, services, assets, and possibilities of access would mean denying them their purpose as humans. Participation is therefore essential to human life. Recent German social legislation attempts to come up to reciprocate this insight by defining participation for each and every group of people in turn and formulating it as a legal entitlement.

The concept of participation, having originated in discussions on the integration of people with disabilities (SGB IX), has in recent years been translated to people with age-related limitations (SGB XI). What became known as the so-called Disability Studies, and the Convention on the Rights of Persons with Disabilities which came out of that, elevated the concept of autonomous living to a political level in a very fundamental way which postulates the application of general human rights in a very specific field. Because it has signed the Convention on the Rights of Persons with Disabilities, Germany is obliged to implement the ensuing rights of people with disabilities.

The German term Teilhabe is also related to the English term participation in the WHO's International Classification of Functioning, Disability and Health (ICF) (cf. Dau 2009: 48, Rn 10). It stands in contradistinction to isolation and exclusion, and intends to promote equal involvement in the life of society. Important aspects of this include legal inclusion, actual participation in social life, and inclusion in functional processes such as working life (ibid.: 47, Rn 10). Ethically relevant questions in the dimension of participation are:

- What participation is possible for older people who are no longer or should no longer be integrated into working life? What kind of participation do they wish for?
- What manner of participation is a) envisaged and b) actually promoted by age appropriate assisting systems?
- To what extent do technical assistance systems prevent or impede certain types of participation?

### **SELF-CONCEPTION**

The term self-conception (German: Selbstverständnis) describes the way somebody evaluates and perceives themselves. Of course, factors like illness, age and infirmity affect a person's self-conception. An important factor in somebody's self-constitution is people's recognition or disregard of their illness or symptoms of age (cf. Honneth 1990; 1992). Key to the recognition process and the self-conception connected to it is a society's idea of a so-called normal, healthy, appropriate condition. There is the subjective experience of a condition as so-called elderly, healthy or ill, and then there is the more objectivising view - at least from a medical point of view. When these two perspectives coincide then it is easier to maintain a developed self-conception, but if not, harmonisation is required, and this can work in both directions (for an overview of different concepts of health see Fangerau, Martin 2011).

There are diverse cultural discourses and debates involving aging and its processes (Fangerau et al. 2007), which is why it is difficult to provide a standard, generally applicable answer to the question 'when is one old?'-from a historical perspective at any rate. In recent years the medicalisation of aging has come to dominate public discourse, and this in turn affects the self-conception of old people. By medicalisation we mean (without making any judgement on it) the extension of medical interpretations into areas of responsibility and action that were previously considered the territory of other social systems (Conrad 2007). Wehling et al. (2007) describe four dimensions of medicalisation which touch upon people's self-conception as elderly. The expansion of medical diagnostics has helped pathologise the symptoms of old age, while the expansion of medical therapy has led to the treatment of the symptoms of old age that are not pathological but that are subjectively experienced as objectionable. The detemporalisation of illness by activities such as predictive diagnostics produces so-called healthy invalids who, when elderly, expect soon to fall sick. The medical optimisation of human nature aims to fundamentally modify age-associated physiological symptomsbefore they have even occurred—and to steer them in the direction of an improvement in performance which in each case has to be defined.

Age is predominantly a negatively viewed affair, especially when looked at through a medicalised lens. Age is associated with bodily breakdown processes and sensorimotor and cognitive slowdown symptoms which bring along limitations in mobility, in the senses (smell, taste, hearing, seeing and touch), in strength and stamina, and even in libido. Equally, boredom and loneliness caused by passivity and a lack of activation and interaction can become a problem with age. Given these circumstances, the medicalised observer might well conclude that medical and technical assistance has to be employed alongside social and human help in order to counteract negatively and adversely adjudged conditions of age and aging. However, such adversely slanted views disagree in many ways with the current philosophical and anthropological or theological discourse about aging (see for example Gabriel et al. 2011).

Ethically relevant questions in the dimension of self-conception are:

- How is the question of meaning which tends to pose itself more in old age given space and perspective within socio-technical arrangements?
- To what extent does the tendency to medicalise life also change our attitude to age and aging?
- Which social constraints, direct or indirect, arise because of the dominant images of medicalised and technically assisted age and aging?
- To what extent are standardisation routines established through age appropriate technology?

### **ON THE USE OF MEESTAR**

Now that we have presented the seven dimensions we will take a look at the two other axes of this model for the ethical evaluation of socio-technical arrangements.

### y-axis: ethical evaluation stages

Building on the basis of an escalation model for the evaluation of genetic engineering in humans (Hakker et al. 2009), the aforementioned dimensions are normatively evaluated in four stages in order to obtain an estimate of whether and to what extent an age appropriate assisting system or a configuration of several assisting systems entails ethical problems. The escalation stages can only be used in a meaningful and informative way if we have knowledge of details such as financing, reliability, the type and scope of transferred data, helper structures and so on. When using this model it should also be borne in mind that the seven ethical dimensions (on the x-axis) can conflict with one another. For example a strong emphasis on care in an age appropriate assisting system can have an unwanted influence on the privacy and autonomy of a person. Ethical evaluation of an age appropriate assisting system will only very rarely give rise to a distinct and authoritative evaluation within just one of the stages; instead it is more likely to provide an indication of the points and dimensions at which conflicts exist.

In the model's four stages (I-IV), only stage I is considered harmless from an ethical point of view. The results from the focus group workshops in the ethics study, as well as qualitative interviews, suggest that this evaluation is fairly unlikely in real life. When the focus groups appraised an example of how age appropriate assisting systems could be used, they too applied stages II-IV. That is why the model as extended here works in a different way from the escalation schema developed for biomedical interventions in humans. Hacker et al. observed bioethical applications and attempted 'to define the unproblematic scenario and distinguish it from increasingly problematic scenarios' (Hacker et al. 2009: 47). However, when the escalation schema is translated to the use of age appropriate assisting systems, classification—or distinguishing between two stages-takes place by analysing an actual specified situation, including its technical system, in a methodical fashion within one particular dimension (e.g. care) and on a particular level (e.g. individual level), and assigning it to a stage (I-IV). Evaluation does not involve comparing one situation against another hypothetical one; it always limits itself to analysing an actual scenario. As Hacker et al. have already asserted, the escalation model can only be used within a defined time-frame. Changes that affect factors such as social environment, the loss or acquisition of personal resources, and technical/political developments—all these impact significantly on evaluation and are subject to a dynamic which also has to be taken into account (cf. Hacker et al. 2009: 49).

# z-axis: individual, organisational and social analytical levels

It is an established principle—especially in the ethics of technology and business-not only to analyse normatively relevant behaviour at an individual level but also to include the organisational and social level (cf. Ropohl 1996; Ulrich 2008). That is why the evaluation matrix has a third dimension to it, allowing individual, organisational and social perspectives to be analysed. It is not just individuals who have to be responsible for their actions, but also corporative entities such as companies. One also has to discuss a social level of responsibility. The responsibility of society, in short, lies in the political deliberation of how people want to live in that society and which rights and obligations people have in respect to one another (cf. Heidbrink, Hirsch 2006). The model also enables the viewpoints of numerous stakeholders to be ascertained and taken into account in evaluation (cf. Bleisch, Huppenbauer 2011).

### Scope and benefit of MEESTAR

MEESTAR is used to gain an overview of ethical problems and areas of conflict within a particular arrangement of one or more age appropriate assisting systems. MEESTAR structures and systematises one's sensitivity to ethical issues and realms of action, with the aim of avoiding blind-spots. MEESTAR also demands a change of perspective and the consideration of other points of view, things common to ethical reflection. That is why the three levels of reflection are included, to ensure that ethical problem-areas are not considered from one side only. The model should always be embedded with an iterative process. This helps to ensure that the ethical status quo is observed and constantly evaluated as social, individual and technical phenomena develop.

MEESTAR does not supply evaluations which can claim to be universally or timelessly applicable. Rather it is an instrument for ethical location and clarification at any given time in order to gain insight into ethical apprehensions and areas of concern or no concern in the way actual age appropriate assisting systems are used. MEESTAR cannot supply a quantitative evaluation of the scenarios it examines. Ethical evaluations are qualitative by nature; quantitative features and aspects can feed into them, but they cannot produce a quantitative evaluation result. Furthermore, the necessary assessments of values and assets need always to be renegotiated. These processes of negotiation are, according to the thinking behind MEESTAR, performed in groups, a process which aims to ensure that different points of view are not only identified and documented, but also dynamically discussed. Only a mutual processing of arguments for and against within the seven ethical evaluation dimensions can achieve the necessary depth of reflection needed to evaluate a given scenario.

# 5. Ethical guidelines for the use of age appropriate assisting systems

The purpose of these guidelines is to provide some orientation for dealing with assisting systems in the everyday lives of elderly people, and to engender some sensitivity around ethical decisions, judgements and actions. When we formulated these guidelines we took into account other guidelines and behavioural requirements that have been developed and presented elsewhere (Bondolfi et al. 2003; Gothe et al. 2010; Meyer, Mollenkopf 2010). The guidelines are not rigidly fixed and should be understood as proposals for building understanding of age appropriate assisting systems. We expressly encourage their development, revision and correction. Each guideline consists of a key phrase followed by a detailed description.

### **1 – AUTONOMY**

### Age appropriate assisting systems should help users to lead an autonomous life.

Age appropriate assisting systems should be designed in such a way that their users can continue to autonomously decide and act within the technically assisted areas of their lives. The age appropriate assisting systems themselves should not make decisions, unless such an action on the part of the system has first been configured with the consent of the user. The use of fully automatic, self-deciding systems requires a separate assessment. Furthermore as a matter of principle it should be possible for users to shut down these systems themselves (either temporarily or permanently). Suppliers and users need to be informed about such shutdown mechanisms. The responsibilities and liabilities around users shutting down systems themselves need to be regulated and communicated in layman's terms.

### 2 – RESTRICTED AUTONOMY

# Age appropriate assisting systems should only be used to help cognitively impaired people following a special assessment and taking into consideration the probable wishes of such people.

Users who suffer from cognitive impairment, such as those suffering from dementia, should, together with their relatives or representatives and at an early stage in proceedings, clarify their own wishes and attitudes towards the use of age appropriate assisting systems; or this should be achieved by means of other arrangements (such as advance consent); or by nominating a caregiver.

Technical assistance applications should only be used for people no longer capable of making decisions following explicit consultation with their relatives or caregivers, and in compliance with legal regulations.

### **3 – PARTICIPATION**

# Age appropriate assisting systems should support participation in social life and integration into social relationships.

Age appropriate assisting systems should enable (easier) access to social life (such as by assisting with communication and mobility). People's own ideas of participation should have precedence, which means the system should not encourage particular kinds of participation. This goes for the participation of users as well as participation among the people offering care and support. Furthermore, assisting systems should not supplant or prevent other ways of enabling participation (such as through personal friendships).

### 4 – JUSTICE

### Access to age appropriate assisting systems should be without discrimination.

The ideal aim is to provide access to age-appropriate assisting systems which is independent of income, social status, age, gender, educational level and technical affinity, and which is just and without barriers.

#### 5 – SAFETY

# The use of age appropriate assisting systems has to be safe and secure for all user groups, both in normal usage and if faults and breakdowns occur which affect the whole system or certain parts of the process.

Age appropriate assisting systems should not compromise security in the sense of the physical or mental integrity of users or providers. Nor may faults, functional breakdowns, process interruptions, network problems or any other technical defects or human errors impair or endanger the health of the people involved. Age-appropriate technical assistance systems may not incur additional physical or mental burdens such as stress, mental overload, discrimination or stigmatisation.

### 6 - PRIVACY

# Age appropriate assisting systems should not have a negative effect on the way people shape their own lives.

The collection and processing of data which is passed on to third parties from the private realm of people using age appropriate assisting systems must be done in such a way that additional information (such as linked information) cannot be derived. Warning signals and messages should be pseudonymised and, where possible, anonymised. As with all data-processing systems, the collection and passing-on of data from the heart of the private realm of users of age appropriate assisting systems needs to be secured by special protective measures. The protection of this data is especially important, and that includes avoiding its merging with data from other users.

### 7 – DATA PRIVACY

Personal data and other confidential data collected, documented, evaluated and stored in the context of age appropriate assisting systems should be protected in the best possible way against access by unauthorised third parties and against misuse.

Third parties may not access or process users' personal data without authority. This includes accessing data belonging to medical or nursing personnel (employee data privacy). Data privacy declarations should be written in a simple and clearly understandable way. In the event of doubt, decisions should always fall in favour of those from whom the data originates. The precautions needed to uphold data privacy and the right to informational autonomy, and behavioural guidelines on how to correctly handle such sensitive data, should be communicated in a clear way and made transparent.

### 8 – NOTIFICATIONS AND INFORMATIONAL SELF-DETERMINATION

Users of age-appropriate technical assisting systems should be informed in full about the function and collection of data relating to them and the function of the system, and should not be asked to give their consent except on that basis.

Users should be informed in detail, fully, clearly and appropriately about the scope, context, depth, purpose and data usage of the age appropriate assisting systems concerned. Users should not be asked to decide on the use of assistance technologies except on the basis of that information.

### 9 – LIABILITY

# Responsibilities and liability in the event of a malfunction in age appropriate assisting systems have to be transparent and regulated in a binding way.

Responsibilities and liability risks in highly complex systemic solutions need to be precisely defined. Responsibility vacuums should be avoided. Responsibilities should be clearly defined for each age appropriate assisting system and its functions (see also ULD 2010).

### **10 – CONCEPTS OF AGE**

### Age appropriate assisting systems should permit as many different concepts of age as possible.

A one-sided, adversely slanted picture of elderly people should be avoided, as should an unnaturally positive image of elderly people as vital, capable, disciplined human beings. One-sided views do not do justice to the complex phenomenon of age and aging. Furthermore, it is important to take into account all the different aspects of aging in social discourse without adopting selective and/or discriminatory positions and/or setting up standards. The use of age appropriate assisting systems can therefore be viewed as an inspirational prompt by which to initiate throughout society an open discourse on aging well.

### **11 – AVOIDING DISCRIMINATION AND STANDARDISATION**

Stigmatisation and discrimination are undesirable in the context of using age appropriate assisting systems. Similarly undesirable are direct or indirect standardisations that issue from such systems. Whether or not a person opts for an age appropriate assisting system is a personal life decision. The principle of equality ought to apply in order to avoid discrimination. The use of technology can, sometimes inconspicuously, exert a standardising effect, such as in cases when people adapt themselves to technical rhythms and routines and/or orientate their everyday lives around measured values and base their actions on them. Subtle effects of this kind need to be disclosed. If they are perceived as unwanted interventions into an individual's way of life then such subliminal or open standardisations ought to be avoided.

### 12 – USABILITY

# Age appropriate assisting systems should be designed so that their use is simple, intuitive and easy to follow.

Key to usability in age appropriate assisting systems is that they are simple to grasp and use and that the systems' ability to alleviate burdens and provide support is recognisable. This must especially be the case in the context of potentially older users who may have impaired sensorimotor capacities, restricted mobility and reduced cognitive capacities (such as memory) and will therefore place demands on technical systems that differ from other people's. Demands and user interests must be taken into account when planning, designing, testing, marketing, applying, developing and maintaining age appropriate assisting systems (see also Friesdorf et al. 2011)

### **13 – CONTRACTUAL REGULATIONS**

When using age appropriate assisting systems it should be possible to exit from contractual relations if users feel insecure, unhappy, observed, or impaired in their privacy, or are concerned in any other way. Generally applicable contractual foundations do have to be upheld so that the suppliers of age appropriate assisting systems can plan on a reliable basis. The users of assisting systems should first be given the opportunity to test a technical application in detail before opting for long-term use. Modular assisting systems can help to achieve the greatest possible flexibility in this respect.

### **14 – QUALIFICATION AND FURTHER TRAINING**

# All of those involved in the field of age appropriate assisting systems should participate in regular training and educational activities.

The suppliers of age appropriate assisting systems need to feel obliged to train and qualify themselves regularly in the field of age appropriate assisting technologies. This implies the consideration of user acceptance surveys and user wishes as well as a basic knowledge of legal, economic, ethical and social issues.

### 15 – RESPONSIBILITY AND THE BEST POSSIBLE SUPPORT THROUGH TECHNOLOGY

# Suppliers of age appropriate assisting systems should behave responsibly; assistive technologies should always be employed for the benefit and wellbeing of users.

The primary aim of age appropriate assisting systems is to meaningfully augment human assistance, care and management among elderly people, and in doing so offer clear added value to everyone involved. Technology serves people and should adapt itself to their needs, wishes and life processes—not the other way around (see also 11—Avoiding discrimination and standardisation). Technology should not restrict the processes of life in an unwanted way or demand too much adaptation from users. This is why it is especially important that the benefits and added value of technical assisting systems are clear for everyone involved to see and understand. Added value can manifest in different ways for different user groups (those requiring help and care, professional/semi-professional carers, service providers, payers and so on), and should be clearly depicted. Services and/or technical options should only ever be employed with the consent of the users concerned. Conflicts between different user groups should be communicated openly and proactively in order to find solutions.

### 6. Ethical tipping points and areas of conflict

The term tipping point describes a visual dynamic. It is rather like the kind of trick image in which two things are depicted but only one of them can be seen at any one time—depending on how you look at it. We use the term tipping point to describe those awkward transitions at which the technically positive effects and morally beneficial aspects of age appropriate assisting systems tip over into their opposite. This is less about the fundamental ambivalence inherent in technology as such, but more about changes to socio-technical arrangements over time, from being helpful support systems to becoming counterproductive burdens. For this brochure we have selected and described some tipping points as examples. In doing so we have oriented ourselves around the seven dimensions and three levels used in the MEE-STAR evaluation instrument.

### How to shape participation?

What should people participate in nowadays, and in which way? The answers to this can vary in their sophistication, and some of them might have the potential to be conceived as excessive demands. The actual participation needs of older people may not have been sufficiently researched in all their diversity—but we can still say from an ethical point of view that enabling participation should not transform into forced participation—such as that which can be engendered by general social expectations.



#### Figure 2:

Ethical tipping points and areas of conflict—illustrated as examples in the MEESTAR structure

Concepts of participation, personal responsibility and autonomy have to reflect people's actual capacities. For instance, when we promote participation among people with disabilities, the idea of reintegrating them into the job market usually underlies our actions. The possibility that they might earn their means of living by their own work and thus be able to plan their lives economically is a powerful and plausible guiding idea. But where does one integrate people who are no longer able or obliged to work? That is not a question which can be answered as part of the application of age appropriate assisting systems, but it does shed light on the broader context within which decisions on their use will be made.

It should after all be borne in mind that age appropriate assisting systems help people in a phase of life in which activity is gradually reducing. Systems that support participation and autonomy—activity in other words—have to be designed so that they do not obstruct the tendency to decelerate and become more passive.

# Burden and relief in socio-technical arrangements

Assistive technology which aims to enable people to live longer autonomously at home can under certain circumstances cause the loss of those very abilities required for such autonomous living—if, for example, the technology takes away so many burdens from people that their basic abilities gradually decline (regression). This is how short-term relief can, over the long term, turn burdensome. While individuals may wish for this it may be less desirable socially—and vice versa. The different levels of analysis (individual, organisational, social) need to be brought together to identify ethical problems and tipping points of this kind.

### Technology as a disciplining measure?

The aim of many age appropriate assisting systems is to establish security in a way which guarantees bodily integrity. But that which a particular person may consider safe and secure can never be a rigid set of rules to be transferred into an arrangement which will then satisfy the individual needs of large groups of users. For instance, if we define thresholds for the monitoring of vital statistics which delineate the corridor of what is considered 'normal', then this should not be done with a disregard for individual differences in the way people live their lives and in their varying constitutions. Furthermore, it has to be remembered that even if defined limits and thresholds are broken (and of course if they are not), the state of users and their personal desire for support should be paramount. The definition of values that help describe the behaviour of users and their condition within the continuum of normality and variation therefore touches upon the issue of the standardising character of such systems.

# How should age-associated restrictions be differentiated from disabilities?

A socio-politically meaningful differentiation between age and disability (SGB XI and XII and SGB IX) can lead to the parallel development of assistance systems for both groups of people; this then needs to be justified in terms of the politics of their funding and the resources utilised. Assistance systems should be developed and offered in accordance with the need for help if they are to be financed through care and health insurance funds. It is here that the phenomenon of aging brings with it a difficulty: various unavoidable processes of degeneration take place in people as they age and these should be considered normal. The question is whether and to what extent, or at which point, we should intervene to counteract these degenerative processes and at what point may support actually overburden those affected.

Some of the assisting systems aimed specifically at older citizens may under certain circumstances be just as useful for people with disabilities. Support offered by the health insurance funds under SGB IX is comprehensive, unlike the care insurance provided under SGB XI which is intended only as partial coverage. Some socio-political clarification will be required before introducing systems in order to prevent injustices.

### Relieving carers – or creating a demand for more of them?

The projected use of assisting systems shows that many technical arrangements entail a high demand for personnel. Not only does this have to be financed, it also has to be supplied with a workforce. This places a certain amount of doubt on the aim of using technology at least to relieve caregivers and thus alleviate shortages in nursing staff. Even if the use of technology stabilises the demand for caregivers, it may well entail a much more costly demand elsewhere for people such as those who maintain the technical systems. This is why an overall economic account needs to be drawn up in terms of financial expenditure and benefits; and the effects such technology might have on the labour market need to be assessed. Then, on the basis of these more rounded assessments, we will have to broach the topic of how funds can be distributed in an ethically, socially, politically and economically appropriate way.

Note should also be made of the difficulty of the instant care approach which is demanding widespread structural changes on the supplier side. Instant care refers to the spontaneous deployment of carers and nurses among older people. The instantaneous caregiving which this aims to supply can probably not be provided with the personnel currently available. For this reason suppliers are preparing to include informal helpers, but this could lead to a dependency situation of considerable risk. Private, voluntary and civil-society commitment to older people in need demands a very large pool of volunteers to cope with spontaneous, unforeseeable assignments. And yet it is first and foremost the unemployed and underemployed who have a relatively large and reliably disposable time-budget. There is therefore a danger that the care and support of vulnerable people will be delegated to similarly vulnerable other groups.

The points of view and interests of relatives have so far remained largely uninvestigated. We therefore need to find out what form of relief and help they, as people directly affected, hope for from age appropriate assisting systems. This will allow us to derive indications of the likelihood of such systems' success and the extent of their use. Systems and solutions should exhibit benefits that are directly recognisable by the various user groups and payers.

### **Urban-rural divide**

Rural and sparsely populated regions already suffer considerable infrastructural problems in areas such as public transport and the provision of powerful broadband data networks. Mobility and informational connectivity are moreover key components of age appropriate assisting systems and of the normative demand for caregiving, security and participation. Healthcare systems would however be unable to finance such infrastructural measures; and in any case it does not belong to their remit. The question of how to distribute burdens fairly, which poses itself in many social contexts (the cost of living-space and mobility, environmental burdens, quality of living) will be modified once again by the use of age appropriate assisting systems. So far however, these questions have not been sufficiently dealt with or discussed.

# Just access to the necessary assistance systems

If age appropriate assisting systems are not to be financed through health insurance funds, then their cost will need to be covered directly by private households. This would be relying on a supply and demand structure which can get out of its depth: if the market for age appropriate assisting systems does not cover all of the areas which necessarily need to be served, then needy people will have to be helped in other appropriate ways. It is not yet clear how this could be financed just.

In one way or another it is always the patients and needy who have to come up with the money for age appropriate assisting systems. But two of the very reasons why they need these systems are firstly that social ties-primarily families-now often exist only in rudimentary form because of education and working activities, and secondly that social networks-friends, neighbours, clubs and so on—are becoming weaker since geographical mobility is making it more difficult to build up and maintain such networks. At the same time, private care brings other social problems with it since it is mostly women who provide care services and who therefore find it more difficult to develop their own life-plans. The fundamental question therefore remains as to which social resources we can and wish to mobilise socially in order to cope with the social dimension of the caregiving problem.

### Medical or lifestyle product?

Clearly, users are sometimes only interested in the opportunities and limits of age appropriate assisting systems when they need acute support. Because of this there is the problem of having to respond at short notice. Ideally, people should become acquainted with age appropriate assisting systems at an early stage so that they can get to know the features well and provide their informed consent. But at that early stage the need for assistance is not always so clearly defined as to provide the medical indication which would permit assisting services to be financed through a health insurance fund. This discrepancy in timing needs to be productively dealt with by the various service providers in conjunction with those affected.

Some products developed as age appropriate assisting systems can be marketed as convenient lifestyle products outside the realm of age and disability. Purely private financing is expected in such cases. However, when users do make the transition from independence to a situation deserving support, we can expect enquiries about the partial refunding of the assistance systems they have financed themselves. A clear boundary needs to be drawn between that which is financed in a solidary way and that which is paid for privately. It will also be essential to define the status of age appropriate assisting systems: what is classified as a medical product and what is a lifestyle product?

# Autonomy, assistance and incorrect operation

Even if different cognitive and motor faculties have been assumed for the products we analysed (e.g. autonomous blood pressure measurement), we have to assume, especially in people changed by dementia, that misoperation will occur and produce unwanted and sometimes serious consequences. One feasible solution would be to develop systems so that these users cannot or do not have to manipulate them. A modular assisting system or one built up in stages could accommodate different levels of autonomy. As a consequence, a continuous evaluation process will be required to determine whether a user's level of autonomy still correlates with the system's degree of assistance.

# Are individual and social care structures changing?

The fact that humans are able to care for each other is what makes them moral beings. Human care is not just bilateral, it can be organised in larger social units over and above relations between those nearby (family, friends, village communities). And beyond the interpersonal dimension, care is a characteristic of the welfare state and should therefore be considered one of the bonds that tie society together. What is therefore ethically relevant is whether using age appropriate assisting systems to provide older people with household assistance will change the gestalt of care and thus change the coherence of society as a whole. Our study showed that there are at least indications that assisting systems are changing the face of care and that mutual care and sympathy between human beings could be replaced by technology. This however is not a result of the technology as such, but rather of false hopes and misguided expectations associated with its use (Manzeschke 2011).

### Can care be delegated to technology?

Alongside this fundamental question is the more pragmatic issue of how age appropriate assisting systems will have to be designed and used so that they do not subvert and corrupt the caregiving aspect. Care must not be subverted by the structures and surroundings of a care system which, although well intentioned, aims to return the activity of caring back into the autonomous and independent charge of those receiving care—and that includes if this is done by way of technical support. What is at issue is to shape the structures of care systems such that both poles, autonomy and care, are treated sensitively so that care does not become a type of besiegement and autonomy does not become a means by which to cloak our ignorance of the needs of others.

### How fragile is the care and health system?

Age appropriate assisting systems are designed to relieve burdens and provide support. That means firstly for needy elderly people, secondly for their relatives and their near neighbours, and thirdly for professional carers. Assisting systems can relieve the burdens of one or all of these groups of people, but they can also add burdens to individuals and groups alike. When it comes to balancing the factors of relief and burden, we will not always be able to determine from the outset who is to be relieved of which burdens and how. But whatever the case, these considerations need to be transparent and done with the mutual consent of those involved. Furthermore, a socio-technical arrangement has to be observed and evaluated over time since it can reach a tipping point whereby what was once a relief eventually becomes a burden-and vice versa. Such changes are closely connected to the restrictions that arise through age, and which restrictions are considered worthy of or requiring support.

### **Summary and outlook**

People should be able to shape their own lives. Age, disability and the need for care can massively limit autonomous living and social participation. Age appropriate assisting systems are designed to counter these limitations. The consistent observation of ethical, legal and social aspects will help to ensure that age appropriate assisting systems do not just serve individuals but also contribute to a society in which people in all their diversity can live well with each other. This is a primary examination of the ethical aspect of the use of age appropriate assisting systems. Three key components of the study on ethical issues in the context of age appropriate assisting systems have been gathered in this brochure. Firstly (1) the MEESTAR instrument which helps and assists in the systematic evaluation of socio-technical arrangements. As well as that (2), we have developed and presented 15 ethically normative guidelines designed to provide everyone involved in the context of age appropriate assisting systems with some orientation for the decisions and actions they take. Finally (3) the results have been summed up in a detailed final report. This brochure gathers together the findings and results of the study and also sets out the need for further research. More work is needed, including in the following areas and on the following subjects:

- A deeper examination of gender-specific and of migration-related aspects is required in the context of age appropriate assisting systems in order to record variances, requirements, needs and different expectations.
- It is equally important to reassess the concept of disability in terms of the benefits and specific application contexts of age appropriate assisting systems. Age appropriate assisting systems cannot be conceived of, developed or offered without relating to aspects of disability – fundamental clarification is advisable in this area.

- It also seems essential to look more closely at the issue of the foundational mechanisms upon which supply and demand structures will be established in the field of age appropriate assisting systems. This includes determining factors which will encourage or reduce the acceptance of such systems among potential users.
- It is also important, as well as supplying and promoting age appropriate assisting systems, to reflect on other ways of promoting wellbeing among old people within their own four walls, and in so doing to expand the spectrum of possibilities. Ethical evaluations should, in conjunction with legal, economic, social-science and technical considerations, contribute towards achieving practical alternatives in solving this problem.
- It will be similarly important to examine the whole area surrounding the issue of aging well (including aspects such as mobility, work, family, volunteering and so on). It will not be enough to illuminate and examine merely isolated aspects of aging well, such as the field of assistance technologies in the household. Rather it appears necessary and advisable to think in more fundamental terms about the various (individual, organisational and social) concepts of aging well, and to analyse and evaluate these within a broader context – that of the pursuit of the good life.
- If like Norbert Elias (1939) we consider the 'Civilising Process' as an internalisation of what are initially external necessities and constraints, then it would seem advisable to look more closely at the configuration of preventative health politics, technical monitoring and control aspects and economic frameworks, and to identify civilising benefits as well as dangers within historical longitudinal surveys as well as ethical/anthropological reflections.

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