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# Welfare Technology Dilemmas facing Young People with Intellectual Impairment – some illustrated Theoretical Explorations

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### Abstract

The introduction of new technologies, specifically Welfare Technology, is examined in this article. Illustrative examples and experiences from young adults with intellectual impairments are provided as input to our theoretical discussions. A theoretical examination of dilemmas linked to the development and introduction of WT technology within the welfare society is offered, with challenges and dilemmas linked to inclusion and exclusion. Enhanced inclusion may be supported by WT technology and promote possibilities for self-determination. On the other hand, necessities to provide surveillance may stigmatize a person as someone unlikely to take responsibility for his/her own life. Special attention is offered in this respect to issues of ambiguities and dilemmas regarding the introduction of WT in the areas of health care and social work. Three issues will be explored in relation to this area: *Knowledge- and skill requirements, technological challenges* and *involvement/user participation* accompanying control and monitoring purposes.

Keywords: Welfare Technology, Intellectual Impairment, User Involvement

### Introduction

In the coming years, Norway and the Nordic countries will face a range of challenges due to significant demographical changes within the population. As with most industrialized countries, these challenges may have a detrimental effect on the provisions of public welfare. It will presumably become much more expensive because the older population is growing, while there are fewer people left to help pay for them (Preisler 2014). Welfare Technology (WT) is therefore launched as an important contribution in order to face these challenges.

In Norway, both the government and an increasing number of municipalities have been running a range of WT pilot projects for the last couple of years. In general, the target groups in these projects are older people, as young adults with intellectual impairments have received less attention despite the fact that they require facilities from the public as much as elderly people (Laberg 2011).

Over the past two decades, there has been tremendous change in the technologies that we exploit to support the communication of individuals with significant disabilities. Mainstream consumer technologies (e.g. tablets, smartphones, telecommunications tools), enhanced displays functions and speech output options provide much greater flexibility, portability, affordability and acceptability among targeted groups (Bradey et al. 2016).

This article directs attention to the possibility for WT to support, empower and increase self-management among young adults with an intellectual impairment. Instead of *passive care taking*, the focus is shifted towards the option of becoming acknowledged and *active* members of the community (Law and Moser 2007; Swartz and Watermeyer 2008). WT technology could play a crucial role in this respect, as the strategic application of WT could be shifted from a focus where target groups are perceived as simply being *passive receivers* of information and support. Alternatively, the view could be shifted towards an emphasis on target groups as more *active searchers for useful* information and support. Consequently, our aim will be to examine how targeted groups are capable of utilizing WT solutions to help manage their daily living in areas such as communication, housing, work and social interaction/networking.

The following questions will be addressed: What possibilities may WT provide to make users able to increase their capabilities in a 'self-serving society'? How may dilemmas such as inclusion/exclusion be transformed from paralyzing and hampering into innovative interventions? Will young people with intellectual impairments run the risk of becoming utterly stigmatized when compensatory WT solutions are introduced?

In order to examine these dilemmas, this paper will *explore knowledge- and skill requirements users' and families' position in relation to communication support*. Technology for tracking and monitoring, as well as technology for long distance treatment, raises basic ethical challenges for surveillance, autonomy, confidentiality and privacy (Hoffman 2012). Here, the private-public dilemma operates as yet another challenge. Important in this respect will be to justify how the use of the Communication Support System (CSS) appears supportive to our targeted group. We will attempt to bring forth some benefits, but also possible ethical and physical barriers and dilemmas, though determined and decisive statements regarding benefits and solutions will not be addressed.

Our basic assumption in this respect is that phenomena in our current society are ambiguous and appear as dilemmas, rather than being either/or. We are inspired from research in other areas, such as organizational science, in which dilemmas and ambiguities have recently received greater attention (Jason 2013; Smith and Lewis 2011; Weick 1995). This emphasis supports an approach where coping capabilities in order to handle dilemmas and ambiguities become important. The main objective will be to enhance our capacities to face challenges following the introduction of new technologies. This is especially true with new technologies such as WT, which produce uncertainties and unexpected consequences to our daily living in general, in addition to our target group: young adults with intellectual impairment.

# **Conceptualizing WT**

WT is presently developed and introduced more or less without the previous experiences of the challenges and dilemmas facing the growing utilization of this technology within different user groups. Identifying the challenges and dilemmas evolving along the introduction and application of this technology is important in order to explore ways of coping with these challenges and dilemmas. In our explorations, a qualitative approach and a theoretical discussion can help to provide the grounds for more specific further empirically sound research based on the initial knowledge of the field for research we are diving into in our current context. Theoretical considerations and illustrative examples can provide the necessary and useful conceptual knowledge for our initial reflections to qualify for more empirically related investigations.

WT is one important approach to improving services the provided by the welfare society in order to make them more efficient, which is closely linked to Ambient Assisted Living (AAL). AAL covers concepts, products and services that interlink and improve new technologies and the social environment. Whereas AAL focuses on addressing the needs of the ageing population, WT addresses not just older people's needs, but also those of other public service users such as young adults with an intellectual impairment. WT solutions might additionally fulfill needs in a wide range of arenas, including schools, daycare centres, private homes, leisure activities, etc. (design–led innovations for active ageing 2013).

Challenges appear regarding dilemmas linked to inclusion and exclusion. Enhanced inclusion may be supported by WT technology and be supportive of self-determination. By contrast, the necessity to provide surveillance may stigmatize a person as someone unlikely to take full responsibility for their own life.

The dilemma between surveillance and participation is just one of the many dilemmas facing the introduction of WT, with expert-driven innovations and user involvement being yet another dilemma. Coping with these dilemmas is essential in order to manage the challenges they produce, specifically regarding our target group. Before presenting theoretical models that are produced in order to understand disability, we will put forth some approaches to what the term WT encompasses.

There are many definitions and descriptions of what the term WT encompasses. As a starting point, WT can be said to cover technological solutions that help to preserve or develop welfare services at home, during leisure time, at work or at school (Mørk 2010). The term is therefore linked to the operations of public welfare in modern industrial societies.

Services are provided that either compensate for- or support an impairment or disability; as a result, the technology and services can take different forms. One form emphasizes *communication support* such as technologies for real-time audio-visual contact, physical activity monitoring for ageing people and ID cards that control admittance for service providers. *Compensatory technology*, or assistive technology, includes safety systems (alarms for heat, light, locking doors), security alarms, mobility technology, wheelchairs for stair lifts, help in eating and drinking, cognitive training and assistance. Other forms comprise help *to everyday practice*, such as housekeeping and exercise (Hoffman 2012).

Because WT includes many different forms, the paper makes an argument for the importance of Communication Support System (CSS) solutions, including real-time visual contact, global positioning systems (GPS), smartphones with memory support and so on. This covers technological solutions, in which the focus is mainly on communicative aspects and their potential to increase and facilitate these processes for persons with different impairments. These solutions will apparently make a positive impact on the lives and independence of people with ID.

The communicative aspects of target WT solutions can be argued to compensate for a range of disadvantages in many important respects. This article emphasizes self-management as a

key objective (Pols 2012), which is an aspect of 'activity politics' to empower persons with impairments through WT solutions. It is part of the foundation for the specific aspects and WT 'philosophy' that we want to attract attention to.

# **Previous research**

Reference to previous research is a way to enhance our knowledge in the field we are investigating. Previous research regarding WT, with a particular focus on dilemmas that appear in this respect, is scarce. This is specifically related to our target group. In our context, it is important to acquire knowledge of previous research related to WT in order to qualify and conceptualize this field for further empirically based investigation.

There is a range of research in the field of computer-assisted devices that describes their presumed beneficial outcomes. On the other hand, there seems to be few empirical studies that can document such outcomes (Hoffman 2012).

A literature review (Devik and Hellzen 2012) focusing on older people and computer-assisted devices (real-time audio-visual contact and monitoring for symptoms) demonstrates that there are a number of solutions accepted as useful for both users and their families. There seems to be less research on user needs, advantages/disadvantages and how to implement WT in everyday life; hence, more research and illustrative case material is needed. A qualitative research design may also provide added value in this respect (op. cit.).

The Social Policy Research Centre (SPRC), University of New South Wales, conducted a literature review about the role of assistive technology (AT) in support of people with physical, sensory and communication disabilities and complex care needs.<sup>i</sup> This review explores whether using AT has the benefits of improving the quality of care, deferring functional declines and institutionalization, improving quality of life, enhancing social inclusion, reducing the level of unmet needs and alleviating pressures on the existing long-term care system (Thompson, Fisher and Keyess 2013). The overall conclusion supports a tendency towards a positive assessment of the benefits and potential of AT for all concerned (op. cit.).

The Ethical Framework for Telecare Technologies project (EFORTT) counts as another example. This project examined the ethical, social and gender implications of technological care interventions for older citizens in Spain, England, Norway and the Netherlands. Material from Norway was based on the examination of two different interventions: The Security Net and the use of GPS devices in dementia care. Participants involved in the first intervention found this network of contact and services to be very important. They were in daily contact with each other, with other network members taking the a form of an extended family. Experiences were shared with the staff at a base station, and linked directly to the municipality's services. The informality in these relations lowered the threshold for getting in touch. The base staff got in touch with participants through two-way contact, which enabled them to continuously update the situation. Simple technological solutions seemed to make significant improvements for the individuals using them, and the final report concluded that societies need more creativity in order to provide care that is meaningful, sufficient and dignified (Mort et al. 2011).

A Norwegian study (Øderud, Grut and Khan 2015) supports the study presented above. It demonstrates that the use of GPS is useful for people with dementia, as well as for family and professional caregivers. The study reveals that using GPS for locating persons with dementia provided an increased safety for all stakeholders. Persons with dementia maintained their autonomy and continued their outdoor activities despite the progression of the disease, so to some extent they were able to enjoy their 'previous freedom'.

Moser and Thygesen (2013) examine how new technologies in health care may influence the ways of providing care. They based their examination on the use of GPS in the care of dementia, as the authors argue that the introduction of Telecare directs attention to new strategies for WT in care service provision. Telecare is directed towards new ideals and strategies that emphasize self-determination, independency and the capacities to govern one's own life.

Another study (Dahle Alvseike and Brønnick 2012) exploring the possibilities of elderly people managing eBook readers and computers revealed that cognitive disabilities and low self-confidence in coping may reduce the possibility of using the new technology. This is somewhat contrary to the more positive results addressed in the previously presented studies. Here, we are faced with the possible dilemmas prevailing with WT.

As with any use of WT, this indicates the importance of linking the technological solutions closely with capabilities to manage the introduced solution in ways that improve self-management capacities. A *passive control* through the application of GPS does not in itself provide the user with the improvement of self-management capacities. Equally

important would be to provide a GPS that supplies ways of *actively engaging* the user in their mapping of surroundings and the location of places, people or services of immediate interest.

# **Theoretical framework**

# Models of disability

The objective of this study is to illustrate and analyse the issues, ambiguities and dilemmas emerging with new technologies, in which special attention on the development and introduction of WT- and CSS-related solutions is given. Thus, the involvement of WT or CSS affects various actors in various situations. In order to more closely investigate the way our targeted actors are affected, we need to know some more about them.

Theoretical models are providing assistance in our approach to disability. These models are important, both to consider and apply, in the analyses of everyday experiences since they provide options to identify dilemmas and ambiguities when WT/CSS solutions are considered that affect citizens considered to be target groups.

A number of theoretical models have been produced in order to understand disability. These include the individual or medical model, the social model and the bio-psychosocial model (BPS), with each model having different implications for how people with different impairments/disabilities are approached.

Unlike the social and medical models, which respectively consider a disability as arising from social barriers and from the individual that need to be fixed, the BPS model considers the interactive nature of disability (McKenzie 2013, 370).

The medical and social models are often presented as contradictory, although they are not necessarily viewed as purely medical or purely social. This requires proper and suitable responses, so when considering WT/CSS solutions both models can therefore be of significance (WHO 2011).

McKenzie (2013) observes that neither of the two models (medical and social) has provided a comprehensive theoretical or practical foundation when issues related to disability/impairment are presented and analysed. Instead, he is arguing for models that emphasize the *interactive nature of disability* (370). More interactive models acknowledge functioning and disability/impairment as a dynamic interaction between health conditions and contextual

factors, both personal and environmental. Among the *contextual* factors are external environmental factors, such as social attitudes, architectural characteristics, legal and social structures and climate/terrain. *Internal personal* factors include features such as gender, age, coping styles, social background, education, profession, past and current experience, overall behavioural patterns and individual characters. All of these are more distinctly present when disability/impairment is experienced by individuals (WHO 2011), though a focus on the interactive nature of disability/impairment is largely associated with Nordic countries. This 'Nordic' approach arose within a context of deinstitutionalization and alternative forms of welfare provision (McKenzie 2013, 372).

One objective of a presentation of a 'bio-psycho social model' is to direct attention to a workable compromise between medical and social models. Accordingly, in the context of this model, a high value on social inclusion and partnerships with enlightened professionals is emphasized (McKenzie 2013). Partnerships and inclusion are features, whereby WT can gain significance as a means to support the enhancement of these objectives.

### Social inclusion

The WHO (2011) describes intellectual disability as a significantly reduced ability to understand new or complex information, and to learn and apply new skills (intellectual impairment). Some experience intellectual impairment as a reduced ability to independently cope with challenges faced in numerous situations in daily living (impaired social functioning). For some, the intellectual impairment starts before adulthood, and has lasting effects on the overall process of socialization and development.

The report: *The Case for Change* (WHO 2010) focuses on children with intellectual impairment in the European Region. In this report, attention is given to the transition taking place regarding the general attitudes and approaches toward intellectual impairment. This transition has become significant, not just across the European Region, but also more globally. Important in this transition is a shift from models based on segregation in institutions, to models that give priority to community-based living and social inclusion.<sup>ii</sup> This has implications for health-care services, as well as for the entire range of social and educational services. The transition also has far-reaching implications for how people with impairments, particularly children and their families, are provided services and live their lives (2).

As is now commonly accepted, a different diagnosis requires the assessment of adaptive skills (e.g. communication, self-help, community living) and intellectual functioning. Here, WT/CSS may play a major role in a way similar to how adjustments of the physical environment have improved conditions for more purely physical impairments.

Current policies governing services for targeted groups in Western countries aim to maximize their social inclusion, independence and empowerment (Scior 2011). Around the globe, policies and services are being put in place to assert their rights and tackle barriers to their inclusion (op. cit.).

The experience of social inclusion for people with different impairments is reflected in the opportunities, services and attitudes present in society. The levels of social inclusion have been closely linked to living situations related to living independently in the community, living with parents, sharing a home with a few others or living in large institutions. Increased opportunities for education, employment, recreational activities and leisure activities have additionally made a significant impact on social inclusion.

Moreover, the overall living conditions and opportunities available to people with different disabilities/impairments are significantly influenced by the attitudes of society (Hall 2010). This can be viewed as being in accordance with a social and interactional model of disability. Large–scale deinstitutionalization in the US and many European countries over the last few decades support these trends. In these countries, an increased community inclusion is reported (Scior et al. 2013). Nevertheless, whether this implies an *actual* social inclusion is still a matter for debate (1015).

One aspect that contributes to social inclusion is the willingness of members of the wider community to welcome and accept individuals with different individual disabilities/impairments in their midst (op. cit.). Engaging in interactional events, as well as developing and maintaining networks of friendships, is an important aspect of social inclusion. Social inclusion implies exercising meaningful social roles that may take place in the family, workplaces, activities and a wide range of social contexts within the community (Hall 2010). This is where WT/CSS may support or even remodel a progressive inclusion evolvement, although this does not take place without challenges related to dilemmas and ambiguities. Whether an *actual* progressive evolvement takes place is a matter of measuring progress, which is out of the scope of this article to judge.

#### User involvement and user-driven innovation

User involvement is an ambiguous challenge related to the dilemmas previously addressed above. On the one hand, user involvement supplies a crucial input to the development of WT/CSS technology. Here, end users are viewed as the ones who most notably experience the need and requirements that WT/CSS solutions can help fulfill. By contrast, users may not be aware of their own needs and possibilities. Even more important in this respect is the possibility that in some instances users are incapable of advancing meaningful decisionmaking contributions in the process of creating and implementing WT/CSS technology.

How to involve service users within more marginalized groups in a meaningful way has been acknowledged and discussed (Hoole and Morgan 2010). Much investment has also been made in order to find ways of supporting people with learning impairments to gain more control over the services provided, as well as their entire life condition. One aspect of this advancement in control capabilities implies an ambition to become more actively involved in decisions regarding individuals' daily lives through changing service structures and philosophies (op. cit.).

In the development of WT/CSS products and services in the Nordic countries, a relatively high degree of *user-driven innovation* is emphasized. The term *user-driven innovation* refers to processes, whereby users provide necessary and crucial information about their own situation and needs. A further ambition is to engage users in processes in which solutions are developed and implemented. This deals with insights on both an observable and more latent level, both of which are quite difficult to grasp (De Moor et al. 2010). The intention of user-driven innovation is to ensure that the new solutions truly resolve the specific problems of the various user groups, in addition to satisfying ethical standards (Mørk 2010).

Several approaches have been put forth in order to provide participatory and collaborative knowledge where user involvement is emphasized. These include approaches such as voice of the customer methods and lead user methods (De Moor et al. 2010), with the latter referring to users of a product or service who currently experience needs still unknown to the public (op. cit.).

Traditional user research tools include focus groups, surveys and participatory or user collaborative research approaches. These are methods that primarily focus on what people say

and think. Methods from other disciplines are also used to dig more deeply into what people do or want, such as ethnographic research, observations and user toolkits (op. cit.).

An important philosophy in this respect comes from the Social Construction of Technology Theory (SCOT). This theory argues for the importance of the social context that technology is embedded in, as technology has to be considered as a product of human action and social structure. Producers have to make profits, and power structures have to be handled to help determine the choices of technological solutions. Furthermore, many irrational and arbitrary events guide the choices and trajectories<sup>iii</sup> that technological developments take (Bijker, Hughes and Pinch 1987).

#### Approaches and ambiguities

Different models of disability can appear to be ambiguous regarding the application of WT/CSS solutions. The introduction of WT/CSS can be based on a professional identification of user needs and achievable solutions. Governments and the public can also promote the development of certain technological trajectories through innovative policy decisions, which is more of a 'top-down' approach with less of an emphasis on user involvement. It is here that exclusion from real participation, self-fulfillment and communicative interaction based on fundamental democratic acknowledgement runs the risks of being downplayed. As a result, conflicts with user involvement, empathy towards user needs identification and the stimulation of user-driven innovation possibilities may come into play as well.

Models that emphasize the interactive nature of disability assumes an association with a more bottom-up approach. The surveillance aspect is therefore being downplayed, with more of an emphasis on solutions motivating the user to self-determination. Through specific CSS solutions, users may become motivated to take initiatives in order to communicate their needs and proposals. Social media, smartphones and IPads are examples of existing technology that may work as the foundation for more of a bottom-up and interactive emphasis. Users becoming more *active* and *participative* in the development and implementation of solutions is one important aspect in this respect, while another would be to develop technology that *'in itself' would stimulate user's self-determination*. This could make user themselves more active in providing and seeking information to produce satisfactory solutions. This could appear as a pathway to become more acknowledged participants in their own community context.

# Methodology

Our approach is qualitative in order to support a theoretical discussion, as the focus is on dilemmas and how to cope with them. Examples and illustration will be provided, discussed and analysed in order to enhance our reflective capacity, thereby making us better fit to make qualified choices and find ways to cope with challenges facing the introduction of WT.

The illustrative dilemmas operate as biographical and self-biographical short stories (narratives), with most of them strictly personal (Hammersley and Atkinson 2007). They function as a kind of "sensitivity training" (ibid) that underpins our theoretical discussions and conceptual clarification. In our discussion, as well as in future research, their general validity can be investigated further through more quantitatively based empirical research.

In the field of social science, collaborative and participatory research has gained a major focus for both criticism and attachment. Action research has argued its position as having other collaborative forms of research (Greenwood and Levin 2007; Støkken, Johannessen and Natland 2011). The voice of the practitioners, users, communities, works and organizational members has increased in importance. Methodological approaches within social anthropology, sociology, social work and social pedagogy have founded the legitimacy of such approaches. In this article, we do not elaborate on method or methodological considerations, and here are just a few remarks.

Qualitative approaches can be considered useful in mapping and analysing aspects of WT communication solutions. Understanding the knowledge- and skill requirements that users and families hold in relation to WT may contribute to revealing interviewees' own perspectives. Qualitative approaches will contribute to bring forth technological challenges that may arise for users and families specifically regarding dilemmas that occur.

Empirical material, and storylines/experiences from the field of the daily life of users and families, may provide examples intended to illustrate the theoretical and descriptive presentations. The examples utilized in this article are based on discussions about WT and housing involving interest groups of people with disabilities in a specific region in Norway.

Five users and eight family members between the ages of 20 to 62 participated, with the participants including 11 women and 2 men.

Invitation letters were sent out via leaders of two interest groups of disabled people in a region in Norway. The regional committee of the interest groups approved the study and the recruitment process, and the Data Protection Office of Research on Norwegian Social Science (NSD) authorized it. The discussions were conducted in five municipalities in Norway in the spring of 2014. Additionally, specific expertise, as well as examples from the literature, have been consulted.

Methodologically speaking, this is in accordance with Durkheim, who in his methodological considerations emphasizes that empirical material is first and foremost illustrative and produced within the intention of comparative purposes (Gane 2010; Durkheim 1985). The intention of the current article is to describe and understand more than confirm and prove, as it is for those advocating qualitative methodologies, such as for instance 'grounded theory' (Glaser and Strauss 1967).

# **Exploring dilemmas**

When events appear as dilemmas, they more or less occur as contradictory or ambiguous (Jay 2011). Dilemmas can be experienced as double binding, in which the actor is put in a situation with no way to create a definitive and unambiguous outcome (Batson [1972] (1999).

In our context, introducing WT could simultaneously produce both surveillance and enhanced self-determination. An option in this respect would be to avoid WT solutions at all.

Thus, reflecting on challenges and ways to cope with them can produce a capacity to cope with dilemmas in a way that makes it more favourable to introduce WT solutions. Whether our final choice will be to emphasize favourable or non-favourable aspects, the point to be emphasized here is to make us capable of making choices in the first place.

User involvement implies an enhancement of the capacity to make choices based on the ability to figure out challenges and deal with them. This is why our methodological approach in this article is qualitative and illustrative, in order to better understate our theoretical discussion. The objective is that we acquire more knowledge in order not to be paralyzed, but positioned in order to cope with the dilemmas occurring along the introduction of WT.

### Control and participatory acknowledgement

Control is mentioned as an aspect of concern on many occasions. Cameras, alarm systems and sensors are examples of control systems that create a sense of being observed. Users within such control regimes can experience that these solutions may limit their possibilities to communicate and participate.

Participation and communication is addressed as having a great potential regarding the application of WT/CSS. Participation is experienced as a necessity in order to create an ownership to the solutions selected, as a lack of participation can create resistance and defiance. On the other hand, solutions themselves can support and facilitate communication.

### Participation in decision making regarding GPS solutions

Participatory aspects concern the decision process by which the WT/CSS solutions are chosen, directing attention to the importance of the social model. Participation is important in both the processes *prior* to the presented solution and to the *results* achieved. User-driven innovations and participation secure the acknowledgement of users. This indicates how interaction with the environment is important to consider, as indicated by the interactive model previously presented.

The following example may illustrate some of the topics addressed above:

A user moves out of the original family location to a new separate home of his own. Regarding coping capability, the user cannot handle any form of traditional technological solutions like fire - and residential alarms. Still, some technological accommodations were implemented, such as bathroom and toilet facilities. The public providers had not considered the new smart house technology or applicable communication technology. This was the case, despite the expressed need from the user's parents to address new possibilities more closely linked to CSS-based solutions.

One of the new solutions that the parents expressed a great interest in was GPS tracing. According to the parents, this might enhance the freedom of movement for this user, especially the freedom of movement in the outside environment.

Moser and Thygesen (2013, 144) present an example that supports some of the 'freedom' experienced with the use of GPS. Their example is based on an interview in which a close relative tells her story about her husband and his dementia. A key topic in the interview was

their experience with the use of GPS tracking technology. Her husband enjoyed long walks, even after his dementia made a significant impact on their day-to-day living. Little-by-little, she experienced that he got more and more frequently lost. His wife got ahold of GPS technology that was linked to both her and their daughter's mobiles, and through this solution they were able to continuously keep track of him. According to the informant, this helped them to experience a new life situation.

When topics concerning GPS tracing were raised, concerns and resistance regarding surveillance were simultaneously expressed. Even so, GPS technology was not merely regarded as a part of a stricter control regime, since the freedom acquired through the introduction of GPS was highly appreciated. In contrast to the freedom of GPS, more concern was expressed regarding cameras and auditory monitoring equipment.

Freedom related to the private sphere was not only linked to GPS technology. Automated solutions for safety precautions were also highly appreciated in this respect. Fire precautions and exploitation by strangers taking advantage of the users' disabilities were also an area of concern, while several solutions were regarded as an enhancement of self-determination.

### The surveillance and freedom dilemma

These examples illustrate dilemmas with WT/CSS related to the distinction between control surveillance technology and technology supporting freedom. In the social context in which surveillance equipment appears, they may be associated with public control. Respect for privacy implies a protection from public eyes and ears, as privacy laws should protect and secure a reasonable expectation of privacy.

Private/public is a dilemma addressing the wider social aspects concerning disability/impairment. The focus is shifted from the individual/medical focus on disability to the social context and a wider societal environment. Additionally, attention is directed to the interactive nature of the disability presented earlier. Accordingly, both medical and interactional aspects are simultaneously present, which supports the foundations of the bio-psycho social model.

### User involvement and WT/CSS solutions

User participation concerns aspects of involvement in decisive and important improvements associated with WT/CSS solutions. Technology might be regarded as social constructs created

by social actors, whereas users' capability and empowerment to influence the development of these solutions will have a great impact on the day-to-day life of those affected (Bijker et al. [1987] (2012).

Participatory aspects raise important questions concerning users' possibilities to decide on what the best CSS solutions to cover their needs are. Standardized solutions might be based on surveys or mapping to produce a workable image of what user needs are, as needs will be interpreted and reformulated in order for developers, providers and experts to create solutions. Questions regarding the capacities and roles in the decision-making processes on what the needs are, as well as what solutions to provide, might become an important aspect of participation.

Experts and public service providers are acknowledged as important actors in order to introduce optional WT/CSS solutions. Reliable expert knowledge from service providers could compensate for a lack of knowledge and skills among user groups. To what degree users are capable of promoting their needs and advocating suitable solutions is an important aspect of the participatory dilemma.

Social work and technology disciplines are traditionally organized as separate educations in separate organizational units with their own concerns, thereby creating a risk that technological aspects are separated from social aspects.

Technological advancement offers an opportunity for experts and public service providers. This is due to the fact that technology needs to be refitted or adapted for different users, although adapting and refitting technology is often an issue overlooked in the field of the public service provider's capacities (Getz 2012). Nonetheless, public service providers may operate as facilitators between users and the WT/CSS solutions that they can be supported with (op. cit.).

Resistance and even hostility toward public expert interference are occasionally expressed by users and significant persons in social networks. Tensions in the relationship with public service providers are articulated as well, and a desire to be empowered to participate in decision-making processes and applications of solutions has been expressed. User-driven innovation is also important in this respect, as well as more generally in innovation (Poole and Van de Ven 2004).

There is an ambiguity between the trustworthiness of experts and service providers on the one hand, and the acknowledgement and participatory ambitions of users and their actor-networks on the other. Many critical and even hostile expressions emerge among users in relation to this dilemma, since users may wish to be actively empowered advocators in WT/CSS processes. Appearing as passive respondents targeted for the retraction of user information operates in contradiction to the empowered advocators. In this situation, there is an interactional challenge between private users and public professional providers. Increased competencies are therefore required on both sides in order to cope with this situation and the dilemmas involved.

### User participation and interactive information processing - different strategies

Control systems and surveillance technologies are basically a one-way communication through specific information devices. They *inform you* and supply information for users to *react to. Interactive communication technology* emphasizes active users *seeking* and *providing* information.

Many current solutions operating as social media enhance social interactions covering a wide range of arenas. CSS-based media might mutually exchange and process information from the *past* concerning the *present* and targeting the *future;* hence, an *active* and *acknowledged participation* could be required of those involved.

CSS solutions founded on interactivity are basically a two-way communication with a potential for enhancing the great need for users to gain and maintain social relationships. This interactive aspect of CSS solutions might provide an occasion for users with disabilities/impairments to break out of the isolation they might experience.

Individual *passive* users informed by CSS solutions are linking disability to a more individualized medial model of disability. The social and interactive approaches to disability direct attention to aspects of CSS solutions, whereby users may appear as *active* agents seeking and providing information themselves. They provide information in order to participate in decision-making process, in addition to several other aspects of daily living.

Interactivity could be regarded as one of the crucial aspects of CSS linked to an increased quality of life, which concerns important aspects to reach improved standards ('normality') in areas such as work, leisure and health. An ability for an increased communication with their surroundings might be enhanced in ways to compensate for users' intellectual

(communicative) impairments. This is another aspect of CSS solutions that directs attention to the possible interactivity emphasized in the model, in which the interactive nature of disability is focused on.

### Actively engaged versus passively arranged users

Tablet communication with video facilities has been stated as an opportunity in social engagement. For some users managing most ordinary equipment, such as washing machines, stoves, vacuum cleaners and money payment facilities, represents a challenge. By contrast, quite a few are able to manage video communication. For several users, Chat, Facebook and similar communication media can be utilized with only minor- or no adjustments. A further development of adjusted CSS solutions could supply increased social communication opportunities in this respect.

CSS technology could possibly produce increased stimuli deprivation. Instead of actively taking part in social gatherings, users might become isolated *behind* their equipment. They would then run the risk of an increased passivity, as opposed to moving out to physical/social arenas for 'real' social interaction. This operates as an adverse effect of CSS that exists alongside the importance of social media as a means to move *out* of isolation.

### The 'warm hands' dilemma

New technology is often associated with an increased efficiency due to the possibility that CSS solutions can replace human manpower. An outcome of such replacements is at times referred to as the substitution of 'warm hands'. This impact on CSS appears to create less social contact and human interaction, as objectified relationships through technology solutions are put up against subjective emphatic contact with caring personnel.

Contrary statements to these objectifications through CSS can also occur. Surveillance and an increased efficiency can create 'free' resources or 'slack' to be utilized for *new* more qualitative interrelations. One outcome can be that more resources for social interactions with users related to new activities are provided and further refined through WT/CSS solutions.

# Conclusion

Our focus has been on dilemmas occurring when WT/CSS solutions are developed and implemented. One major objective in this respect has been to explore the possibilities and challenges that may occur as CSS is introduced as a mechanism of inclusion in the

community. Moreover, theoretical and descriptive aspects have also been illustrated. Short biographical and self-biographical stories constitute the basic (narrative) material. This illustrative material underpins our theoretical discussion and conceptual considerations, in which dilemmas and ambiguities involved are targeted.

Three models of disability (medical, social and bio-psycho-social) have been presented, with the emphasis on users and human social issues concerning the social and interactive approaches emphasized in the models. The bio-psycho social model has constantly reminded us that there are important medical features involved that comprise basic aspects of the dilemmas presented.

One dilemma occurs between surveillance and communication regarding the use of different types of equipment and solutions such as GPS, cameras and auditory tools. Possible scepticism was addressed in relation to the use of cameras for observing movements conducted by the user. On the other hand, GPS tracing was regarded as more of an option for increased 'freedom', predominantly phrased as freedom of movement.

Dilemmas related to the lack of participation in CSS solutions provided by the system of experts and public services have been addressed. Users' and the family's lack of participation has created resistance and defiance, while users might be involved through user-driven innovation, decision-making processes, the mapping of needs, etc. User involvement/participation additionally raises questions and dilemmas related to the capacities users possess in order to express them.

Users may wish to be empowered in order to be actively involved in decisions, development and the implementation of solutions. Even so, they may acknowledge the role of the experts and professionals when it comes to decisions and choices regarding CSS solutions. This paradox may be related to the interactional challenges that exist between the private users and public professional service providers.

Encouraging an active user is an important challenge for CSS technology that implies a specific competence-building initiative in order to provide users with the necessary skills and capacities to become active users. Significant others in the user's network also require skills and competence building to become active practitioners.

In accordance with the bio-psycho social model, CSS solutions themselves have to be arranged with the necessary features to facilitate and encourage the active user, taking into account the different impairments which occur. Medical impairment could be compensated through WT solutions. Instead of just supplying control and surveillance technology, the providers of CSS solutions should be inspired to supply solutions that enhance the capability of users to become active participants. This could be part of an important ambition in order for users to become self-determined acknowledged actors in their community environment.

Based on our examination, one could be inclined to ask whether there are ways to overcome barriers and uncertainty appearing toward WT/CSS technologies. Questions could also be raised as to whether we should support the use of WT/CSS technology for the user. One answer in this respect is that there is obvious support for the application of WT/CCS technology in the examinations we have provided in this article, although the answer is not certain. We are left to handle both the positive and negative aspects. Participation and communication are required for those affected to reach joint decisions, without being certain that we always reach an ideal and definite outcome. We cannot be certain that benefits outweigh the ethical/physical/social dilemmas and ambiguities. Our bio-psycho social model could help be a facilitator in this respect.

Possible ways to face the challenges addressed have been examined in relation to topics such as: *knowledge- and skill requirements, technological challenges* and *involvement/user participation* accompanying control and monitoring purposes. They are related, but provide us with no definitive answers, thereby addressing the necessity for further research, examinations and investigations.

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<sup>&</sup>lt;sup>i</sup> In the review (SPRC), complex care needs refers to both multiple care needs and serious care needs. The former are needs that can only be met by the provision of multiple, integrated services, while the latter refers to needs that require intensive, high level support (Thompson, Fisher and Kayess 2013).

<sup>&</sup>lt;sup>ii</sup> In 1988, the Norwegian Parliament voted for a mandatory dismantling of all institutions for intellectually impaired persons in Norway (Tøssebro 2013, 72).

iii See Dosi et al. (1988).