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Assistive technology, telecare and people with intellectual disabilities: ethical considerations

J Perry,1 S Beyer,1 S Holm2

ABSTRACT

Increasingly, commissioners and providers of services for people with intellectual disabilities are turning to assistive technology and telecare as a potential solution to the problem of the increased demand for services, brought about by an expanding population of people with intellectual disabilities in the context of relatively static or diminishing resources. While there are numerous potential benefits of assistive technology and telecare, both for service providers and service users, there are also a number of ethical issues. The aim of this paper is to raise these issues and to set them within the ethical framework proposed by Beauchamp and Childress. There is a need for a wider debate as a first step in the development of strategies to address the issues raised in the paper.

The US Assistive Technology Act of 1998 defines an assistive technology device as “any item, piece of equipment or product system, whether acquired commercially, modified or customised, that is used to increase, maintain or improve functional capabilities of individuals with disabilities” (Section 3, a, 3). This definition encompasses items ranging from walking sticks to the latest augmentative communication or environmental control devices. The current paper relates specifically to electronic assistive technology the use of which has accelerated exponentially in recent years both in the fields of services for older people and, most recently, services for people with ID. The increased sophistication of communications hardware coupled with technological developments in devices such as sensors (eg, gas, flood, movement and temperature sensors) has created the potential for vulnerable people to be monitored remotely and supported as needs arise rather than having to be supported by staff directly and irrespective of immediate need. Tang et al describe telecare, as it has come to be known, as “… the delivery of health and social care to individuals within the home or wider community outside formal institutional settings, with the support of devices enabled by information and communication technologies”. Telecare, has been in use for several years in services for older people. Indeed, Doughty et al identified a progression in telecare services for the elderly from reactive systems requiring user-initiation, through “automatic” reactive systems (eg, sensor-based) to third generation “passive” systems in which possible acute situations are predicted on the basis of “lifestyle monitoring”. Increasingly, such systems are now being applied to services for people with ID.

The UK government is committed to investment in “preventative” technology; £50 million is available to local authorities in the current financial year through the preventative technology grant, with £30 million having been available in the 2006/2007 financial year. The purpose of the grant is to initiate a change in the design and delivery of health, social care and housing services and prevention strategies to enhance and maintain the wellbeing and independence of individuals. This is in keeping with the Department of Health’s ambition to make home “telemonitoring” available in all homes requiring it by the end of 2010. Expansion of telecare is also consistent with the white paper Our health, our nation, our say: a new

1 The Act is designed to support programmes of grants to States to address the assistive technology needs of individuals with disabilities, and for other purposes.
The practical implications of the Mental Capacity Act and the principle of autonomy more generally, which are relevant to the application of AT&T in the field of ID, include the areas of effective provision of information, awareness of the issues of response bias and potential for unintentional coercion, and the right to privacy.

Response bias

There is a wealth of research evidence that people with learning disabilities have great difficulty responding to questions concerning abstract matters and are more prone than the general population to response bias (e.g., 17, 18). One example of response bias is “acquiescence” which is the tendency to respond positively, regardless of the question being asked. Another example is “recency” which is the tendency to select...
the last of two possible response options. For example, if asked whether they want tea or coffee a person might say “coffee”. However, if the question was phrased “do you want coffee of tea” they might say “tea”. High levels of acquiescence amongst people with ID are frequently reported (eg,18-22). Heal and Sigelman23 suggested that people with ID may say yes to many yes-no questions in order to be agreeable and may say no to questions that mention socially undesirable behaviours to deny any association with these taboos. Sigelman et al24 reported that recency bias characterised an average of 21% of paired answers in three samples. Heal and Rubin27 reported recency bias at 10% in their study of 91 adults with ID. Perry and Felce25 examined responsiveness and response bias using a random sample of 154 people with a range of ability levels. They found that only the most able third of people with ID responded to questions about satisfaction with various aspects of their lives without response bias. Therefore, the answers provided by people with ID should not necessarily be taken at face value. Just because someone says they have understood what has been said might not be enough. It might be better to ask some simple questions relating to what has been described so that it can be established if the person genuinely understands. Indeed, the Mental Capacity Act now requires such functional tests to be undertaken if capacity is in doubt. This is not undermining the person’s autonomy or being disrespectful; the purpose is to safeguard their interests.

Coercion

Most carers, whether relatives or paid staff, want the best for the person they support and would be outraged at the idea of forcing people with ID to do anything against their will. However, coercion can be quite subtle and unintentional. For example, in the field of ID, AT&T is a new and exciting area with potential for enhancing quality of life. It is easy for policy makers, service providers and front-line carers to become enthused by, or even evangelical about the prospects of what might be achievable. However, if this enthusiasm comes across too strongly during the process of gaining consent, there is a distinct possibility that the person with ID might feel pressurised to consent. Again, there is research evidence which suggests that the reasons why people acquiesce include a wish to give socially desirable responses especially if the person asking the questions is perceived as being of higher status than the respondent.22 Conversely, people might be coerced into saying no to AT&T when it may be in their best interests to agree to its installation. For example, staff may be fearful of the introduction of new technology and how it will influence their work, and there may be a temptation to pass on perceived fears to service users.

The right to privacy

Many features of assistive technology are designed to reduce risk and to remove the need for a constant staff presence in people’s homes. To achieve this, homes are fitted with various sensors which will detect problems and alert staff. For example, sensors fitted in the floors of various rooms will enable those monitoring the sensors to know whether a person has got up in the night to go to the toilet, while a chair occupancy sensor would provide information about whether a person has spent an undue length of time without moving. Door sensors and the global positioning system potential of mobile phone technology can even be used to monitor whether someone has left the house and pinpoint where they are in the community. The idea of monitoring activity to reduce risk appears benevolent.

However, other words which could be used to describe the process are surveillance and tagging. These terms have negative connotations, being linked with invasion of privacy, intrusion on civil liberty and association with criminal behaviour. While AT&T is seen by some as providing comfort and protection, it is seen by others to be at odds with human dignity and freedom. The incorporation of Article 8 of the European Convention on Human Rights into UK law by the Human Rights Act 199826 created a general right to respect for privacy. Article 8 is really about intrusion by the state into a person’s private and family life, home and correspondence, but it is framed extremely broadly and does include surveillance. While, overt surveillance by a care provider with a person’s consent is very different from covert surveillance (eg, phone tapping) by the state, the principle is the same.

Better survival of people with ID at birth and increased life expectancy because of advances in healthcare means that the number of people in need of care and support is increasing. However, generally, the resources available to those responsible for the care and support have not kept up. AT&T appears to be a potential solution to the increasing pressure which service providers are under to provide high quality services within constrained budgets. Telecare is advantageous to service providers because, theoretically, staff can be allocated to where the need is greatest. However, it should not be forgotten that many of the management practices associated with institutions in the past were adopted because of convenience to the organisation according to Goffman’s concept of total institutions.27 Such practices included what Goffman termed as rigid routines, block treatment, deindividualisation and the distancing of staff from clients. With this in mind, benefits to the individual and the organisation should be weighed against possible disadvantages for the individual in terms of the impact of surveillance/monitoring on privacy.

Complicating factors

A number of suggestions have been made above about how the issue of autonomy might be considered in relation to AT&T and people with ID. In practice, however, there may be factors which complicate further, judgements about the extent to which the principle of autonomy has been compromised. For example, typically, smart home technology relies on a central hub to which various sensors can be connected and through which a “remote” control centre is alerted if sensors are activated. Those manning the control centre then initiate an appropriate response. A situation might arise where one individual living in a shared house consents for the hub to be installed whereas another individual in the same house withholds consent. In this situation a decision has to be made as to whether to deny the first person access to the equipment because the other individual has withheld consent. Typically, there are two types of assistive technology installation in group living situations. The first involves the introduction of individualised assistive technology, such as an adapted television control, or a thumb-print lock on their room door. Individually tailored assistive technology has minimal impact on co-residents and consent beyond the individual concerned is not required. The second category of assistive technology is that which affects more than one person (eg, general sensors linked to house systems and a call centre line may be linked primarily to one individual (eg, heat or flood sensors where one person regularly leaves food cooking or taps running unsupervised) but still impact on co-residents. If there is a difference of opinion amongst residents as to whether to consent to this category of
assistive technology staff may justify the installation of assistive technology on the grounds of health and safety, irrespective of whether there is unanimous consent. It is not possible to prescribe an appropriate course of action for every eventuality. It is only possible to flag up examples of the ethical dilemmas that might arise so that those responsible for implementing AT&T are able to consider such issues in advance of their occurrence.

**BENEFICENCE**

Beneficence is about doing our best for those who we support. Assistive technology has the potential to benefit people with ID in a number of ways. Simply introducing into a home a computer with internet access and supporting residents to use it can generate an array of positive outcomes. In addition to access to a world of information, computers can provide entertainment (eg, music, film, games), education, a combination of these two (“edutainment”), and they can facilitate a measure of social contact (eg, through interaction via email, and use of blogs and chat rooms). Specially developed software designed for PCs or handheld PDAs can be used to teach home-based or work-based skills. For example, a PDA can provide verbal and iconic prompts for each of the tasks involved in cooking a meal. Increased independence and autonomy can arise from such skill acquisition. Also, by decreasing the need for prompts or corrections by staff, self-managed prompting systems (eg, prompts to alert residents to overly loud music) can reduce inter-personal conflict which might arise between staff and tenants.

The various sensors that are combined to create the smart home may also help to remove dependence on “on-site” support and thereby increase autonomy and independence. Such technology can increase comfort (eg, environmental control such as automated temperature control and remotely controlled windows and curtains) and reduce risk (eg, door entry systems, “chair occupancy” and “wandering client” sensors, smoke & flood detectors). The list of potential applications of assistive technology for people with learning disabilities covers most aspects of life and is constantly expanding. When analysing the appropriateness of introducing AT&T in any given situation from an ethical perspective it is important that the potential benefits which the person might gain are considered alongside any harm which might be caused.

**NON-MALEFICENCE**

A fundamental bioethical principle is that of not causing harm as a result of an intervention. There are a number of areas where AT&T has the potential to cause harm, some more serious than others. They are considered below.

**Stigma**

A simple definition of stigma is that it is a sign of social unacceptability because of “the shame or disgrace attached to something regarded as socially unacceptable”. Link and Phelan proposed that a stigma arises as a product of four social processes. First, people distinguish and label human differences. Secondly, dominant cultural beliefs link labelled people to undesirable characteristics and negative stereotypes. In the third social process, labelled people are placed in distinct categories to accomplish some degree of separation of “us” from “them”. In the fourth, labelled people experience status loss, and discrimination that lead to unequal outcomes. This in turn can lead to anxiety, depression, a distorted self-image and low self-esteem. It has long been recognised that people with learning disabilities can be stigmatised (eg,30) and to counter this many social care providers provide their staff with “values-based” training which, typically, emphasises the importance of people with learning disabilities being afforded status and respect by engaging in activities, and behaving in ways which are perceived to be “socially valued” (eg,31). Parette and Scherer discussed a number of issues related to stigma, three of which are particularly relevant to AT&T: device aesthetics, individualisation and universal design.

The aesthetics of devices is likely to influence how those using them are perceived by others. For example, many people in business settings use personal digital assistants (PDAs). Therefore, a PDA programmed with instructional software in order to support an individual with ID to be more independent in a work setting, is likely to be viewed positively by his or her co-workers. Conversely, hearing aids can lead to the wearer being perceived as elderly, infirm or stupid. For this reason some younger people who could benefit from a hearing aid either do not wear them or hide them. This is why hearing aid manufacturers invest so much in research and development aimed at reducing the size and visibility of the aids. In a similar vein, just as fire extinguishers and exit signs (which are a legal requirement in registered care homes) can give an “ordinary” staffed house an institutional feel, so could the sensors and control panels necessary for a “smart” home if they are obtrusive or indiscreet.

Assistive technology should be tailored to the individual’s needs and preferences. It might be convenient to service providers to install a “core package” of devices in every house because of simplicity and cost-effectiveness, but this is poor practice. Devices which are appropriate for one group might not be suitable for another group. For example, it has been shown that as they age, consumers have a clear preference for products that they do not have to think about, are easy to care for and maintain, and which accommodate to them, not vice versa. In contrast, it might be argued that for other groups (eg, young men) having a home which has the latest high tech “gadgetry” can be a positive status symbol. Individualised, or person-centred, planning is a central tenet of the Valuing people white paper which set out the government’s strategy for learning disability for the 21st century. Those implementing AT&T for people with ID should be mindful of this emphasis on individualisation and aware of the negative consequences which have arisen from a lack of individualisation in past services for this client group.

The term “universal design”, sometimes referred to as “inclusive design”, describes efforts to develop “products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialised design”.35 Assistive technology which is not guided by the universal design concept may benefit people with disabilities but result in separate and stigmatising solutions, for example, a ramp that leads to a separate entry to a building from the main stairway. Universal design strives to be a broad-spectrum solution that helps everyone, not just people with disabilities and it recognises the importance of how things look. For example, while extra thick handles are a way to make utensils more usable for people with gripping limitations, some companies introduced larger, easy to grip and attractive handles and it recognises the importance of how things look. For example, while extra thick handles are a way to make utensils more usable for people with gripping limitations, some companies introduced larger, easy to grip and attractive handles as feature of mass produced utensils. They appeal to a wide range of consumers and reduce the potentially stigmatising image of such objects. In the future, automated homes are likely to become the rule for the general population rather than the
exception, however this is less likely to happen in the case of devices designed to monitor or prompt people. Part of the process of deciding whether particular assistive technology devices are potentially stigmatising is to consider the extent to which they have been universally designed.

Risk
It might have been equally appropriate to raise the issue of “risk” under the heading of beneficence. Clearly, assistive technology such as carbon monoxide detectors provide safety and security which supplements that which would be provided by carers. However, consideration should be given to possible increased risks if assistive technology is used in place of carers. The following case study exemplifies this:

Richard has a mild learning disability and is reasonably independent in most domestic tasks. He can cook simple meals, wash, bath and dress himself and he can wash clothes, make his bed and clean the house. Richard cannot read or write or tell the time so he has support with paying bills, filling in forms, budgeting and time keeping. He is also far less independent in the community. He has limited road sense, is vulnerable to exploitation from neighbours or members of the community.

The organisation which provides the support for Richard is considering using door sensors and a tracking system (through which his whereabouts could be ascertained through GPS [global positioning system] technology) for Richard so that he can have greater privacy and independence whilst at home. The arrangement would be that if Richard wanted to leave his flat, for example to go shopping, he would call the provider organisation which would provide him with peripatetic support for his outing. The tracker and sensor would alert staff manning a call centre if Richard went out alone.

In this example, the proposed assistive technology installation could be advantageous to Richard in terms of greater independence and privacy in the home. It also means that the staff who would otherwise be supporting Richard in his home can be assigned to tenants whose needs are greater. However, there is an element of risk which is introduced by the assistive technology “solution”. The most obvious risks are the inevitable delay which will be incurred while staff respond to the alert received from the call centre that Richard has gone out unaccompanied, and the possibility of technological problems with the assistive technology. From an ethical perspective, leaving aside issues like intrusion of privacy through surveillance, and the stigma associated with “tagging”, it would be important to undertake a specific risk assessment to weigh up the extent of the risk which might exist. Equipment reliability and durability, and the distance between Richard’s flat and any busy roads would be examples of variables which could be considered in the risk assessment.

Social contact
When assistive technology is coupled with operational practices like telecare, as in the example of Richard, the impact on the individual’s level of social contact is also an important ethical issue. It is well documented that people with learning disabilities have very restricted social networks outside of family members and care staff (eg, 34). For many people, contact with staff is the main type of social interaction they have, and staff are often categorised by people with learning disabilities as friends. For example, Robertson et al36 reported that the median size of social networks of a sample of 500 individuals with ID living in the community was five people (range 0–20). The median size was reduced to only two people when staff were excluded. Initiatives such as telecare can lead to reduced staff involvement with people, and any loss of this social contact is something which needs to be factored into ethical considerations. If increased social isolation is identified as a potential consequence of assistive technology in a given situation, consideration should be given to compensatory strategies, such as fostering relations with neighbours or exploring more leisure activities with social contact in mind.

JUSTICE
Beauchamp and Childress1 labelled the fourth principle of bioethics in their framework as justice. In the context of AT&T within the field of ID, justice is partly about respecting the needs and opinions of the individual, ensuring their wellbeing and keeping them informed. These issues have been covered above. Justice is also about fairness and in this respect it extends beyond the individual. For example, decisions have to be made about the allocation of the constrained resources available for human services. The revenue expenditure associated with staffing costs account for about 60% to 80% of residential service costs in the UK.37–41 Although there might be considerable capital costs associated with the installation of assistive technology, one of the arguments in its favour is that, in theory, assistive technology gives staff greater flexibility to support those whose needs are greatest. So, assistive technology, or more specifically, telecare, can facilitate a more rational approach to resourcing. It might appear to be a logical extension of this line of reasoning to provide individuals with every conceivable assistive technology device on the assumption that money might be saved in the long term and that this would allow staff to prioritise their input according to greatest need. However, while it is important to respect people’s wishes as far as possible, a balance should still be struck between an individual’s needs and their wishes. This might mean that a person is denied an assistive technology device which he or she would really like, because a judgement has been made that the money could be spent more usefully elsewhere. Even though such a situation might cause conflict between the person or their family and service practitioners, the purpose of this subsection has been to illustrate that in the interests of justice, resources (both financial and personnel) should be allocated with the needs of the individual and the wider community of people with ID in mind.

RESOLVING ETHICAL CONFLICTS
Typically, there is a tension between one principle and another, and a compromise has to be made. For example, the installation of a “smart” microwave oven which reads barcodes on frozen food packaging and automatically cooks the food at the right setting for the required time could dramatically increase the independence of a person with an ID. At the same time, if support with food preparation was previously one of the main reasons for staff being there, acquisition of the oven might result in a reduction of staff presence and the associated social contact. A compromise might be for the person to receive the oven and for staff to put additional effort into fostering social relations with others.

Marshall13 suggests that the resolution of ethical issues might be facilitated by consideration of the perspectives of “significant” people (eg, family, carers, care managers and friends) on the issue under consideration alongside the views of the person themselves. If the individual is unable to give their views,
Marshall suggests that consideration should be given to what their views might be expected to be. This approach should be used with caution in the case of people with ID because there is evidence of poor concordance between proxy views and those of people with ID.

The Mental Capacity Act also provides a framework for managing capacity to consent. As the application of AT&T to the lives of people with ID increases, there will be a need for case examples on how ethical considerations are applied and conflicts are resolved. Within the context of the Mental Capacity Act there is a need to explore the utility of the various decision-making frameworks relevant to assistive technology, and to refine them as appropriate.

**CONCLUSIONS**

It is important to recognize that the introduction of AT&T is not like any of the decisions that are made in the normal course of providing support. The introduction of AT&T involves a transfer of control from staff, or the person themselves, to a technological system. This involves a change in the normal decision making processes for the person, and potentially a change in the normal safeguards that having staff directly involved brings. It is clear that significant thought is needed in this implementation to ensure safeguards remain adequate in the new situation.

Beauchamp and Childress’s principles have provided a useful framework for examining the ethical issues around AT&T and people with ID. By virtue of the cognitive deficits associated with ID, agencies involved in the implementation of AT&T for this client group face particular challenges in ensuring that “solutions” are ethical. The prospect of changing patterns of staffing which might include reduced staff levels, raise particular ethical issues for people with learning disabilities compared with some other client groups, because of the limited social networks of people with ID and their reliance on staff for social engagement.

Ethical solutions to problems are rarely straightforward. There is a need for experiences to be shared in these relatively early stages of the implementation of AT&T for people with ID so that effective guidance on the associated ethical issues can be provided to practitioners, service users and their representatives.

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**REFERENCES**