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STIRLING



joint improvement team



The Dementia Services  
Development Centre



## Telecare and learning disability

Using telecare effectively in the support of  
people with learning disabilities



# Telecare and learning disability

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Using telecare effectively in the support of people with learning disabilities

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# Preface

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This book explores how telecare can contribute to the support, protection, and quality of life of people with a learning disability. It also considers the importance of telecare in providing support and reassurance to carers.

This is one of a number of publications funded by the Scottish Government's National Telecare Development Programme<sup>2</sup>, in pursuit of the strategic goal of raising awareness of the importance of telecare in contemporary health and social care services. The other books in this series are:

- Telecare and dementia – using telecare effectively in the support of people with dementia
- Telecare and physical disability – using telecare effectively in the support of people with severe physical disabilities and long-term chronic conditions
- Telecare and sensory impairment – using telecare effectively in the support of people with sensory impairments

The books are written for assessors, care and support staff and their managers, telecare service managers and development staff. Senior managers should also find them useful in informing service planning, and they should help raise awareness, expectations and generally advance understanding among service users and carers.

Each book also contains case studies and a training programme designed to help trainers when designing both awareness-raising and skill-development programmes. Programme directors responsible for basic and post-basic programmes for nurses, housing staff, social workers or occupational therapists should consider these as a sound basis for a module on telecare.

Examples of equipment which might contribute to the safety and quality of life of the person utilising telecare are featured in each book. The aim is to support readers by providing information on some of the wide range of telecare products available. The books do not endorse any specific product or supplier, but provide examples of what is currently commercially available or emerging on to the market. Where possible, details of suppliers/manufacturers have been provided at the end of each book.

As we grow older and take on caring responsibilities or become disabled, technology can help us maintain our independence and quality of life.

# 1: Introduction

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We all rely increasingly on technology in almost every aspect of our lives. Within our homes, devices such as microwaves, DVD players and flat screen TVs enhance the quality of our lives and reduce the amount of time we spend on the drudgery of housework. We rely on computers and mobile phones for information, social contact and entertainment, and to help us make informed choices about purchases and services. Away from home, technology such as GPS (global positioning systems) and satnav (satellite navigation) – often incorporated into our mobile phones – has the potential to guide us, keep us in touch, and keep us safe.

People who are more vulnerable and dependent because of a learning disability ought to have the same access to, and benefits from, this increasingly cheap and accessible technology. As we grow older and take on caring responsibilities or become disabled, technology can help us maintain our independence and quality of life. It can also overcome some of the limitations of specific conditions. One purpose of this book is to raise awareness of these issues and provide practical guidance on how to introduce technology to potential service users.

Demographic change, and the key social policy agenda of shifting the balance of care from institutions to care at home in the community<sup>3</sup>, also requires us to maximise the benefits of technology. There is now plenty of evidence to show that telecare can release significant resources from within health and social care systems and facilitate changes in the balance of care<sup>4</sup>. It also has the potential to improve important outcomes such as independence and feelings of safety.

This book will outline how telecare can contribute to improved outcomes for service users. It includes sections on:

- definitions of telecare (along with the related concepts of telehealth, assistive technology, environmental controls, and telehealthcare)
- the importance of good needs and risk assessment if telecare is to help meet those needs and manage those risks
- ethical dilemmas and how these can be resolved
- how needs may be met using telecare as part of a package of care and support
- issues particular to carers
- case studies and an outline training programme

## Definitions: what is telecare?

In this book the term telecare is used to describe the use of equipment within and outwith the home to monitor changing needs and risks, and to provide alerts and information that enable improved and informed responses to those needs and risks.

Demographic change, and the key social policy agenda of shifting the balance of care from institutions to care at home in the community, requires us to maximise the benefits of technology.

The definition below is the one used in the National Telecare Development Programme in Scotland. It forms part of the 'shared vocabulary'<sup>5</sup> agreed and published by the Scottish Government, and is consistent with definitions used in the English and Welsh development programmes.

There is a wide range of telecare equipment, and the scope and sophistication of applications has developed considerably over the last 25 years.

Telecare is the remote or enhanced delivery of health and social services to people in their own home by means of telecommunications and computerised systems. Telecare usually refers to equipment and detectors that provide continuous, automatic and remote monitoring of care needs, emergencies and lifestyle changes, using information and communication technology (ICT) to trigger human responses, or shut down equipment to prevent hazards.

### **First, second and third generation telecare**

There is a wide range of telecare equipment, and the scope and sophistication of applications has developed considerably over the last 25 years. The following informal classification, based on 'generations', provides a way of distinguishing between different stages of development and application.

**First generation telecare** refers to equipment that forms part of most community alarm services. It is used to describe user-activated alarm calls (by push button, pendant or pull cord) to a control centre where a call handler can organise a response of some kind. This is usually via a neighbour, relative or friend acting as a 'key-holder'.

**Second generation telecare** evolved from the introduction into basic community alarm services of sensors such as smoke, gas, heat and flood detectors. Second generation telecare now includes sensors which can monitor not just the home environment, but aspects of lifestyle, physiological measures and vital signs. These sensors can collect and continuously transmit information such as when doors are opened, whether taps are running and the use of electrical appliances. Through passive infrared sensors (known as PIRs), movement both within and outwith the home can be detected. This provides much more sophisticated and comprehensive support for managing risk and improving quality of life. Second generation telecare can also be used to provide data about someone's lifestyle, movements and routines, which can be used for needs assessments.

**Third generation telecare** developed from improved and increased availability of broadband, wireless and audio-visual technology. It offers the potential for virtual or tele-consultations between the service user and their doctor, nurse or support worker, thus reducing the need for home visits or hospital appointments. Furthermore, it provides increased opportunities for people (particularly those unable to leave their homes alone) to 'visit' libraries, shops and maintain contact with family and friends.<sup>6</sup>

### **Telehealth**

In this book the term telehealth refers to the use of monitoring and measuring devices to collect information about vital signs (such as temperature, blood pressure and blood sugar level), symptoms or health conditions in the patient's



home. This information can then be transmitted from the device to a call handler, nurse, or other clinician, who can then advise the patient by phone, text or email on how to manage their symptoms and condition. Clinicians can be alerted to significant changes in a patient's condition, and the patient advised or reassured appropriately. This can take place without the need for a home visit, visit to a surgery, or other consultation. Telehealth is often used to enable people to manage chronic conditions, for example high blood pressure or diabetes.

## Telehealthcare

The Scottish Government has published a paper on long-term conditions<sup>7</sup> which includes a definition of telehealthcare, illustrating how this term emphasises a holistic approach to the person, who should be at the centre of the service:

There is increasing convergence between telehealth and telecare, with the introduction and expansion of remote monitoring as part of the 'telehealthcare' package available in a person's home. Telehealthcare offers a range of care options remotely via phones, mobiles, broadband and videoconferencing. It can improve the patient's experience of care by reducing the need for travel to major cities and hospitals to receive care and treatment. It has been used successfully to provide treatment for dermatological, cardiac and neurological conditions. It enables care to be delivered in remote communities, allows GPs to consult specialists remotely to avoid unnecessary referrals and enables networks of learning for clinicians and maximisation of skill mix for teams.

## Assistive technology

Assistive technology is another collective term for devices for personal use designed to enhance the physical, sensory, and cognitive abilities of people with disabilities to help them function more independently.

## Environmental controls

Environmental controls are equipment systems that enable people with higher levels of physical impairment or chronic health problems to control access to their home, to summon emergency help and to operate domestic appliances. For instance, a single remote control unit can enable a wheelchair user to control temperature and open and close windows, curtains and doors (in addition to the more conventional functions of controlling TVs, DVD players, and audio equipment).

## Telecare as part of a personalised service

Telecare should not be seen as the *solution*, a single one-dimensional response to needs or risk. It is not an alternative to direct care by carers, although it can reduce the need for check visits, 'supervision', or visits to clinics (such scenarios will be explored later in this book). Telecare is effective when it forms part of a personalised programme or package of care and support, and is accepted as such by the service user, their informal carers and other staff/services.

Telecare is not an alternative to direct care by carers, although it can reduce the need for check visits, 'supervision', or visits to clinics.

To be effective telecare requires:

- informed, skilled and personalised outcomes-focused assessment of needs and risk
- resolution of ethical dilemmas around capacity, informed consent and choice (for each individual in each situation)
- training and education for the service user, carers, personal care and support staff in how the equipment can be used or misused and how it should be tested and maintained (for example, battery replacement)

### Telecare services

So far, this introduction has only discussed equipment. The term 'telecare services' sets the delivery of equipment in the wider context of health and social care services. In a practical sense, this means efficient, up-to-date monitoring or call centres with trained staff who have access to personal health and social care data and response protocols. These staff will be available every day of the year, and will be skilled in making judgements about the information and alerts sent by the equipment, and in facilitating the most appropriate response possible. Such centres are absolutely essential to the effective use of most telecare equipment. While different agencies may organise their call handling or monitoring staff in different ways, the presence of someone who can interpret the information, provide reassurance, follow detailed individual protocols, and understand the basics of how equipment works is essential to ensuring the maximum benefit to the service user.

Appropriate response arrangements must also be in place, incorporating individualised response protocols which ensure the best possible response to the immediate need or situation. Traditionally this has relied on 'key-holders' – relatives or neighbours who, when contacted by the call centre, would call on the service user and solve the problem or contact services as necessary. Increasingly, in response to higher levels of dependence and more complex needs, agencies are deploying teams of trained carers, who can respond to an emergency and provide personal care, reassurance, or contact other emergency services as necessary.

In order for telecare services to have maximum impact on wider policy goals such as changing the balance of care, they need to be conceived as part of, and located within, local health and social care strategies for different client and patient groups. Service planners need to articulate how telecare developments will enhance home care and housing support services not as an 'add-on', but as an integral part of health and social care service options.

### Risk and reliability

No equipment can be 100 per cent reliable forever, in the same way that no 'human' service is completely and consistently reliable. Equipment will come with a manufacturer's guarantee, but in the event of a fault an engineer will need to be called out, and there may therefore be gaps in service provision, even when monitoring is required '24/7'. Equipment which relies on mobile phone signals, internet access or landlines to transmit information will, on occasion, experience the lapses in service that affect these systems. To counter these risks, telecare services need to include backup, testing and business

To be effective, telecare requires an informed, skilled and personalised outcomes-focused assessment of needs and risk.

continuity arrangements (although of course equipment purchased privately will not have these safeguards as standard).

'Interoperability' is a significant issue. This refers to the problems that arise when equipment developed by one manufacturer does not work with the call handling or monitoring system which is already in place, and which was made by another company. Progress has been made in resolving this issue, partly due to the introduction of a new (voluntary) British Standard<sup>8</sup>. However, interoperability remains a problem, especially when equipment does not comply with this standard.

It is very important that these issues are taken into account when care packages are being put together through the use of proper risk assessments and appropriate risk management arrangements.

## Access and availability

This book includes examples of equipment that has the potential to contribute to the safety and quality of life of people in need. The examples have not been selected to promote the products of any particular company, but instead to raise awareness of what can be done and what is (or will soon be) available. Where a product is featured, details of the company that sells or manufactures it have been included (see page 39).

Companies specialising in telecare equipment are increasingly able to personalise their products to meet the needs of individual users. Furthermore, they recognise the importance of developing new applications from this starting point. Manufacturers would argue – with some justification – that the scope of what telecare equipment can do is limited by our imagination, rather than by the technology. The cost of equipment is falling, and public bodies now have procurement arrangements in place which should further reduce this cost. In addition, companies welcome contact with service users and professionals to help them understand needs which might be met through new applications.

Some telehealth equipment – blood pressure monitors, for example – can be bought on the high street, and this is a trend that is likely to increase as expectations and understanding of the potential of telecare increases. However, an important part of a telecare service is the response. There needs to be some way in which the information or alert generated by the equipment can be transmitted to someone with the skills and technology to generate a fast and appropriate response.

The major providers of telecare services are local authorities – increasingly in partnership with health authorities. Purchasing budgets are (or should be) available to enable practitioners to access equipment as part of a care and support package. Alternatively, service users should be able to purchase equipment using their individual budgets, or direct payments. In recent years budgets have been enhanced by government telecare support grants, and although some of these schemes may now be coming to an end, health and social care partnerships will continue to explore means of transferring resources so that telecare can develop further using the savings generated.

One consequence of the development in telecare services over recent years is that many authorities have recruited telecare coordinators, or have designated telecare 'champions' within local services. These staff can advise on availability and access, and should find these books helpful in their task of promoting the use of telecare among different client and patient groups.

Telecare equipment needs to be complemented by up-to-date monitoring or call centres with trained staff who have access to personal health and social care data and response protocols.

## 2: Assessment

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An effective and efficient outcomes-focused needs assessment is essential if the potential of telecare is to be maximised. At its best, telecare forms part of an individual ('personalised') package of care and support. To achieve this, individual needs must be identified and telecare then considered as part of the potential personalised response.

### General and specialist assessment of need

Throughout the United Kingdom, community care needs assessment is now conceived of as a multidisciplinary process<sup>9 10 11 12</sup>. In Scotland, much work has been done to encourage the use of 'shared assessments'<sup>13</sup> which gather core data on each individual (such as their name, age and ethnic group) along with information on physical, psychological, spiritual, and physiological needs. The process involves skilled interviewing to elicit what the person's needs are, and what their perception of those needs is at that time. There is an opportunity for a relative or close friend who is a carer to contribute – with the permission of the person. The assessment concludes with a summary of needs, followed by proposals for meeting them immediately (where necessary) and/or as part of a planned programme of care. (This will be dependent on resources being available and on eligibility criteria.)

The possibility of utilising telecare should be introduced during the assessment phase. Just as the person's need for home care, aids or adaptation, counselling or day services is considered, questions in the assessment form ought to trigger a discussion of telecare. During the assessment itself, it is essential to explain what telecare is, using language the person will understand and can relate to. One approach is to start with the (universally familiar) community alarm service, then move to a general discussion of environmental monitoring equipment (flood and smoke detectors for example), before moving on to personal safety and health monitors, where appropriate. At this stage the assessor will be considering the potential contribution of telecare in general terms, as well as introducing the concept to the person and their carer(s).

In some areas, a 'core package' is offered to anyone with community care needs. This might consist of a community alarm and smoke and flood detectors, along with a security device for the front door. Increasingly, in new or refurbished supported or sheltered housing schemes, such equipment is installed routinely. Opinion is divided on whether such an approach is cost-effective or not. Be that as it may, it does not obviate the need for individual needs assessments which will ensure that any additional equipment will meet identified needs.

All assessment documentation should therefore include a section prompting the assessor to consider telecare as part of the total response. It is also important that the assessor has access to information leaflets detailing the range of

At its best, telecare forms part of a personalised package of care and support.

telecare that is available locally, what it is for and who is eligible – along with any costs which need to be met by the service user.

If the assessor believes that telecare can form part of the response and the person agrees, a more detailed assessment is then required. This should include the precise combination of devices which can best meet (in combination with other services) the person's needs, as well as clarifying issues around installation and response. This stage is often referred to as the 'specialist assessment'.

## Specialist assessments

This secondary assessment stage is designed to personalise the provision of telecare by identifying items of equipment that appear to best meet the person's needs. At this stage additional factors – such as the design of the property and the availability of telephone lines, wireless networks and mobile phone signals – will need to be considered. The person's familiarity with electronic equipment will also be taken into account, along with any other telecare equipment already installed. In addition, their routine (for example when they like to go to bed and their sleeping pattern) will also be recorded to ensure that the equipment supports the lifestyle and degree of independence they want. Finally, the integration of the equipment with the rest of the support package, and the need for and availability of a response, will all have to be detailed.

There is no 'best' way of carrying out a specialist assessment. How it is carried out, and by whom, is likely to depend on local arrangements. In some areas, a telecare 'champion' will have been identified within the community care team. This person will have received additional training in telecare and regular updates on the range of equipment available. One of their responsibilities will be to undertake this specialist stage of the assessment, or perhaps to supervise and guide other team staff when such an assessment is needed.

In other areas this task is carried out by a dedicated telecare service. This group will include staff who carry out the call handling, monitoring and installation functions, and they will have links to any response service. The manager of the service, or a designated person, will be asked to take forward the specialist assessment and carry out any installation that is necessary.

## Risk assessment

Risk assessment is a critical component of a good needs assessment. It takes into account the degree of risk experienced by the person, thereby identifying ways in which telecare can assist in the management of risk (by the person themselves, as well as by services). It includes risks in the home as well as outside. These may include risks:

- of fire if the cooker is left on
- of flood if the bathwater is left running
- of scalding in over-hot bathwater
- of unwelcome visitors
- of getting lost
- of harassment
- of hate crime

Shared assessments gather core data, such as the person's name, age and ethnic group, along with information on physical, psychological, spiritual, and physiological needs.

The most basic equipment, such as flood alerts, smoke alerts and carbon monoxide detectors, reduces risk in obvious ways. For people with cognitive impairments (for example arising from brain injury) and some sensory impairments, going outside and travelling can be particularly risky. If the nature of such risks is identified, then appropriate equipment can be selected. This process is illustrated in later sections of the book.

While telecare can be important in the management of risk, it cannot eliminate risk completely. No equipment yet devised is 100 per cent reliable. Routine testing and maintenance (for instance battery changes) are essential to maximise reliability. Even so, malfunctions can occur. Service users – or more often their friends, children or grandchildren! – may inadvertently trigger or disable alarms, and monitoring centres will not always be aware of this. So it is important to allow for reliability and human error in any risk management plan.

### Using telecare to enhance assessment

Some companies have developed equipment which can log detailed information about a person's movement, lifestyle and routines within their home. This is used for needs and risk assessment purposes, as distinct from safety. An example is 'Just Checking'<sup>14</sup>, a portable activity-monitoring system designed for people with dementia (although not necessarily limited to that group). Small wireless movement sensors are triggered as the person moves around their home. These generate an activity chart which can be accessed via a secure website. This very detailed timed data can provide a much more accurate picture of a lifestyle than is possible from conversation with a person with cognitive impairment, or from carers who do not live on-site. Support, protection and care arrangements can then be targeted more accurately in a person-centred way.

### Carers' assessment

In Scotland there is now a duty to offer informal carers an assessment of their needs arising from their caring responsibilities. This focuses on how they can be helped to sustain their contribution to the care of a person in need<sup>15</sup>. Research has confirmed the extent to which telecare can reduce pressure on carers; support them in their caring role; increase peace of mind about the safety and wellbeing of the person they care for; and enable them to sleep better<sup>16</sup>. It follows that a good carers' assessment will include consideration of the potential of telecare to indirectly benefit carers by helping them continue to care.

Recent research confirms, however, that many carers are unaware of the availability of telecare. It cannot be assumed that carers – especially 'new' carers – will be aware of the possibilities telecare offers. Equally, carers will have their own anxieties, and perhaps guilt, about using technology. They may be concerned about its reliability or whether they will understand it and be able to make it work. These issues will be considered in more detail in later chapters of this book. At this point it is important to emphasise that information needs to be made available to carers, and that where a carer's views are sought at the needs assessment stage their perspective and needs should be included and recorded.<sup>17</sup>

Research confirms that many carers are unaware of the availability of telecare.

## 3: Principles, rights and ethics

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The previous chapter described the importance of carrying out a careful needs and risk assessment before introducing telecare. However, while good assessment will ensure that the use of telecare is person-centred and needs-led, it will not necessarily answer the question of whether telecare is 'right' for an individual.

As an example, consider the needs of a person with Down's syndrome who is in the early stages of dementia. The assessment process may indicate that a GPS-enabled wristwatch could reduce the person's exposure to risk when she is away from home. It will enable her carers – and a control centre – to pinpoint her at any time so that they can organise help if she becomes lost or experiences harassment. But the device could also be used to restrict her freedom to go where she pleases, which is a fundamental human right. The telecare device could be perceived as a kind of electronic tag, and this has associations with surveillance and the criminal justice system. Seen in this light, the ethical questions associated with telecare are more sharply exposed.

It may be difficult to comprehensively establish the needs and risks of a person who could benefit from telecare, whether they have dementia, a brain injury, or significant sensory impairment. To carry out an effective assessment, a system like 'Just Checking'<sup>18</sup> might be introduced to their home on a temporary basis. This will provide comprehensive data on the person's movements and routines, including eating, sleeping and toileting. Although the resulting assessment will be very well-informed, this does not necessarily justify the invasion of privacy that is also involved. Similar dilemmas arise with the use of systems such as Betavista which allow control centre operators to see the person in their own home (albeit when an alert is triggered), as well as talk to them on a phone line.

Ethical dilemmas such as these should be considered using the case studies featured later in this book. The purpose of this chapter is to briefly describe an ethical approach to telecare, summarise some principles which need to be considered when decisions are being made, look at the relevant legislation and provide some hints for practice.

It is important to stress four things at the outset:

- each person's needs, choices and beliefs must be a fundamental consideration in any decision
- there are few absolute 'rights and wrongs' which can be universally applied to every situation
- ethical issues are not unique to telecare. Indeed, the principles, values and legal obligations discussed here apply to other care and support settings
- no one acts in a value-free or value-neutral way – we all have our value positions. The important issue is understanding these, articulating them as necessary (particularly to service users and carers) and

This chapter describes an ethical approach to telecare and includes an overview of the relevant legislation and some hints for practice.

understanding and thinking through any conflict that may emerge with the values of others, particularly service users and carers

### Personal value systems

We all take up value positions and have opinions on issues like the smoking ban, how children should be disciplined and capital punishment. Some people consider these issues to be 'common sense' or 'obvious', but in practice they are complex. Our personal values are influenced by the way we were brought up, our education, the apparent values of our community and by our life experiences. For those working in care and support services, there are also our professional values. These are often expressed through codes of practice<sup>19</sup> and feature prominently in our professional education at every level. As a result we learn – and try to integrate into our practice – core values such as a commitment to confidentiality, treating people with respect, maintaining dignity and individuality, and challenging racism, discrimination and injustice.

It is important that practitioners are aware of these values, and how they come to be part of their own value system. It is also important to appreciate that they may not always be shared by individual service users and carers, with the resultant need to resolve conflicts that arise from different value positions.

### Principles

Some writers have developed statements of principles, or ethical theories, which can help ensure that the use of telecare is ethically sound. For example, Bjørneby et al (1999)<sup>20</sup> have proposed these principles:

- **autonomy** – people should be able to decide what they want to happen or be done to them
- **beneficence** – we should try to do good to the people we care for
- **non-maleficence** – we should try to avoid doing people harm
- **justice** – people should be treated fairly and equally

In addition to these principles, Bjørneby suggests that the perspectives and views of all those involved in the service should be sought in relation to both its implementation and the likely impact of its non-implementation.

Kemshall and Pritchard (1997)<sup>21</sup> highlight the values and rights which they believe underpin community health and social care services. These include:

- a commitment to ensuring that all users and carers enjoy the same rights of citizenship as everyone else in the community, with equal access to service provision, irrespective of gender, race or disability
- a respect for the independence of individuals and their right to self-determination, including taking risks, and minimising any restraint on that freedom of action
- a regard for the privacy of the individual, intruding no more than necessary to achieve the agreed purpose
- respect for the dignity and individuality of every user and carer
- to maximise individual choice in the type of services on offer and the way in which those services are delivered

When making decisions about telecare, maintaining respect for the independence of individuals and their right to self-determination – including taking risks – is essential.



- a responsibility to provide services in a way that promotes the realisation of an individual's aspirations and abilities in all aspects of daily life

Cox et al (1998)<sup>22</sup> describe a set of core values that should be incorporated into any person-centred service designed for someone with dementia:

- that the person using the service should have maximum control
- that real and informed choice should be a key part of any service
- that people who use services should be valued and respected as unique individuals
- that continuity of care is built into service delivery in a way that keeps the person in touch with their past and present
- that the person is not discriminated against on the basis that they have dementia or because of any other differences, and that they receive their fair share of good quality and appropriate services

These values and principles provide the basis for rules of practice that will ensure an ethical approach.

### **The law**

In Scotland, three important Acts of Parliament have been passed since 2000: the Adults with Incapacity (Scotland) Act 2000; the Mental Health (Care and Treatment) (Scotland) Act 2003; and the Adult Support and Protection (Scotland) Act 2007<sup>23</sup>. In addition to sharing a common purpose of protecting the rights of vulnerable people, these uphold a common set of principles: that any intervention must be intended to provide a benefit to the person which could not be reasonably obtained without that intervention AND that this is the 'least restrictive' option available. All three Acts also include a requirement to consider the person's views, along with those of significant others, like carers and family. The Adults with Incapacity Act is particularly relevant to this book because of its focus on the rights of people with significantly impaired capacity to make decisions.

### **Capacity and consent**

There will be many occasions when the introduction of telecare raises issues of capacity and consent. The assessment process may indicate the presence of significant risk that telecare (in conjunction with other services) has the potential to reduce. Despite this, the person may refuse the service or be reluctant to accept it. This might be because they disagree with the perception of the risk and/or want to retain the right to choose the way they live.

When working with people who may benefit from telecare but also lack sufficient capacity to make decisions about risk and quality of life, there may be justification for overruling these fundamental human rights. However, these are very significant judgements which should be made carefully and legally. It may transpire that a person's capacity is not impaired after all, but instead their means of communication, or ability to communicate, has not been properly considered. This is generally apparent when the person has a hearing or speech impairment, or perhaps has had a stroke, but may be less obvious when the person has dementia or a learning disability.

There will be many occasions when the introduction of telecare raises issues of capacity and consent.

Where decisions are made on behalf of an individual who lacks the capacity to make choices for themselves, the course of action should be time-limited, regularly reviewed and limited to the particular services and decisions under consideration. Such decisions should never be considered as final or permanent.

### **Policy and procedures**

Individual agencies will have policies, procedures and guidelines in place which ensure that staff remain within the law when delivering services – including telecare services. Implicit in these are the values of the agency, and of the community that it seeks to serve. For instance there will be commitments to equal opportunity, privacy, dignity and confidentiality, alongside procedural commitments to legality, cost-effectiveness and quality.

It is vital that practitioners are aware of these procedures and follow them. In the context of this chapter, practitioners should also be alert to conflicts between the values of users and carers and the values of their agency. These issues are often encountered in the area of risk and personal safety. Agencies have a duty of care, and in some cases their policies and procedures may conflict with the aspirations or expectations of the user, or their carer. For instance, procedures may prioritise the reduction of risk, as distinct from the freedom of someone to take risks and to make their own decisions. Practitioners need to be alert to these conflicts, and to make them explicit to users, carers and their own agency management. They must also ensure that the resolution of the conflict is recorded accurately and transparently.

### **Practice guidance**

In summary, the following guidance is suggested:

- be aware of your own personal and professional value systems – and how these might conflict with the person you are working with and their carers
- be aware of the procedures of your agency, particularly those which are designed to protect the person's right to choose, to dignity, to privacy and to confidentiality
- ascertain as fully as possible the views of the person, their carers and other staff working with them. Do you understand what they are saying to you?
- are there issues of capacity to consent? If so, what are the legal issues around overriding their right to choice and consent?
- in what ways might the telecare solution limit this person's freedoms and rights? Is there an alternative which does not challenge their right to choose?
- how are the decisions to be made recorded? Has a record been provided to everyone who should have one? When is the decision to be reviewed?

Practitioners need to be alert to conflicts between the values of users and carers and the values of their agency.

## 4: Telecare and learning disability

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This chapter explores the potential and value of telecare to people with a learning disability. It begins with some definitions of the nature of learning disability, then goes on to discuss advantages and potential barriers with suggestions for overcoming these. A procedure for bringing telecare into the daily lives of people with a learning disability (including a case study) is then outlined. Where possible, photographs of the pieces of equipment referred to have been included. Numbers identifying pictures also link in to manufacturers' contact details on page 39.

### Definitions: whom are we talking about?

Definitions of learning disability emphasise the need to see each person as an individual and recognise the importance of their choices, access to public and community life, lifelong learning and employment. *The same as you? A review of services for people with learning disabilities*<sup>24</sup> takes this further, stressing the importance of accessing local and specialist services to get help and support so that choices can be made. The review defines learning disability as:

A significant, lifelong experience that has three components: reduced ability to understand new or complex information or to learn new skills, reduced ability to cope independently, [and] onset before adulthood with a lasting effect on the individual's development.

In Scotland it is estimated that around 24 people in every 1,000 have a learning disability with three to four of this number having profound or multiple disabilities<sup>25</sup>. People with a learning disability are now living for much longer. For example, in the 1950s the life expectancy for a person with Down's syndrome was 12, whereas for many today it is over 60<sup>26</sup>. This is due to a number of factors, including improved medical care, especially at birth, and an improvement in opportunities leading to a better quality of life.

The main cause of death among people with learning disabilities is respiratory disease<sup>27</sup> and, as might be expected, life expectancy is at its lowest among those with higher support needs. Crucially, there have been a number of reported deaths that were preventable among people with a learning disability<sup>28</sup>. Taking a person-centred approach to care and encouraging the family and carers of people with learning disabilities to have higher expectations should lead to better quality of life. Similarly, engaging the person in meaningful activities (which have the potential to enhance quality of life) should include consideration of new ways of working and providing support, such as telecare.

In Scotland it is estimated that around 24 people in every 1,000 have a learning disability.

## Communication

Communication warrants a dedicated section when writing about people with learning disabilities because detecting distress or worry becomes more difficult if the person is not able to talk about how they are feeling. Informed consent requires good communication between the person with a learning disability and a carer who is familiar to them. This is essential in making sure that non-verbal signs that can show distress or displeasure are picked up. When explaining how telecare will be introduced and will work, it is essential to use the communication method that the person is most familiar with. If issues of capacity to consent are involved, this will also ensure compliance with guidance laid down by the Mental Welfare Commission for Scotland (2006)<sup>29</sup>. Communication methods can be verbal or non-verbal and may include Makaton, use of pictures, body language or Talking Mats<sup>30</sup>, if this is a style of communication that the person regularly uses. Communication needs may change as the person gets older, so the method of communication used for ongoing consent may need to be adapted when reviewing and evaluating the success of telecare or telehealth.

### Specific learning disabilities and their implications for telecare

Some actions are associated with specific types of learning disabilities. Examples include impulsiveness in Angelman syndrome or psychosis in Prader-Willi syndrome. Before any form of technology can be considered there must be a clear understanding of what may upset the individual, and hence be unsuitable. For example, a person who is afraid of sudden or loud noises will not react well to an alarm that goes off in their room or an automated voice that sounds if they leave the cooker on for too long. This can make a situation worse, and prompt the person to behave inappropriately or even aggressively – yet the response has been caused by the situation and their environment and is avoidable. Other less intrusive interventions, such as silent sensors, may be more appropriate if the person would like to use them.

Health needs will change as the person get older. For example, adults with Down's syndrome are more likely to develop dementia at an earlier age than the rest of the population. This means that lifelong preparation for independent living is not an option as support needs will increase. This does not necessarily make the use of telecare inappropriate. Instead, it means that a review of the method and form of technology used needs to take place on a regular basis to allow for changing skills and capacity.

Communication needs may change as the person gets older, so the method of communication used for ongoing consent may need to be adapted when reviewing and evaluating the success of telecare or telehealth.

## Examples of telecare for people with a learning disability

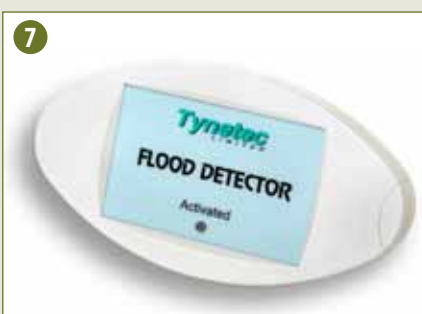
**Pull cord alarm ①.** This can be pulled by the person to activate an alarm which alerts staff nearby or in a call centre. It is only useful if the person is near enough to the cord or able to move to pull it.

**Pendant.** Community alarm equipment which can be worn around the neck ② or wrist ③. A button is pressed to speak to someone at the call centre.

**Temperature monitor ④.** This detects extremes of temperature (hot or cold) in the room where it is placed. The high temperature function can detect a fire or if the cooker has been left on. The low alert can flag up a risk of hypothermia or indicate if a door has been left open.

**Flood detector ⑤ ⑥ ⑦.** This is activated when the floor becomes wet. However, these devices can be over-sensitive and may be triggered by a minimal amount of water.

**Smoke detector ⑧.** This will pick up even small amounts of smoke, although it can be very sensitive to sources of smoke such as burning toast or candles. It needs to be positioned carefully to avoid false alarms.



**Carbon monoxide detector** 9. This can either alert a call centre or automatically shut off the gas supply, although getting it switched on again may lead to difficulties.

**Door contact** 10. This two-part device is fitted to the door and its frame. Staff are alerted when the door is not closed or if it is opened and shut frequently.

**Safe door entry system** 11. This enables the user to see or hear who is outside before they open the door. Some systems are connected to a television so that the person can see the caller before they decide to open the door. Others can record conversations that take place before the door is opened.

**Passive infrared (PIR) beam** 12. This detects movement or lack of movement. It can activate an alarm if there has been no movement when there should be – for example if someone is unable to get out of bed or out of their chair. Alternatively it can be activated if there is movement during the night when this is not expected.

**Medication reminders** 13 use an alarm as a prompt and can help ensure that medication is taken at the same time every day. Some types are incorporated into a wrist watch 14. It is important that the person is not frightened or upset by the sudden noise when the alarm goes off, and if the reminder device is in their house, they need to be at home when it is activated in order for it to be effective.

**Fall detector** 15 16 21. This can be attached to clothes and is activated if the person falls. In order to be effective it must be worn at all times.





**Enuresis sensor** 17. This is a thin sheet that is placed on the bed between the mattress and the sheet. It activates an alarm if the person wets the bed, although it can also be set off by excessive sweating.

**Seizure monitor** 18. This detects seizures by monitoring for movement where it is placed/worn. Monitors are not always effective in detecting minor seizures, although they can prevent the need for staff or parents to check the person so frequently overnight.

**Mobile phone** 19. This can act as a means of communication with carers and family. To be effective it needs to be charged and in credit.

**GPS (global positioning system)** 20 21. A GPS-enabled mobile phone, watch, shoes or other device can be used to locate a person who has left their home but not arrived at their destination. In order for the system to work the person needs to be wearing or carrying the device when they go out.

**Computer with internet access.** Computers can be used to aid life story work using techniques including digital photography.



## Case studies

### Case study 1

Louise lives with her parents and often has seizures at night. Her mother gets very little rest or respite because she is constantly checking Louise during the night. After Louise is provided with a seizure monitor **22**, her mother can sleep knowing that her pager will go off if Louise has a seizure overnight.



### Case study 2

Pauline has just moved into her own flat with outreach support from staff. Her family are concerned that she may forget to turn off the cooker, especially as staff will no longer be on hand to check. A temperature monitor **23** is installed in the kitchen so that a selected telephone number is automatically called if extremes of temperature are detected in the kitchen. If this happens, staff will be notified and will visit Pauline immediately, providing help if needed.



### Case study 3

Anne has been given a phone with additional picture buttons **24** corresponding to family members and staff. These can be programmed to speed-dial the person pictured. She doesn't always remember when she last spoke to her family and sometimes calls them up to 50 times a day. In addition, she can't remember how to use the answer phone so doesn't pick up any messages. Despite the valid idea of using photographs to help Anne identify who she wants to phone, the benefit of the phone is only partly being seen by Anne and her family.





#### Case study 4

Emma has a medication reminder that is programmed to go off at 5.15pm daily, a time when she is always at home. This is a trigger for her to get a glass of water and take her prescription for hypothyroidism. The medication automatically comes out of the pill box **25** at the set time. Not only does this ensure that she remembers to take her medication (which she frequently forgot to do before the system was introduced), she now takes it at the same time every day, which means that she is getting the maximum benefit from it.



#### Case study 5

Bill lives alone and staff worry about him answering the door to strangers at night. His door phone system **26** enables him to speak to the caller before opening the door. It includes the option of recording the conversations he has through the intercom so that if a problem arises (for example there is an adult protection issue) this information can be used as evidence. To protect Bill's privacy his conversations are not routinely listened to, although the information is available if an issue arises.



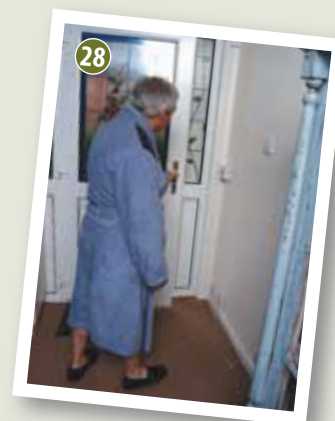
#### Case study 6

Paula has built-in safety equipment in her flat including a smoke detector, a carbon monoxide detector and a flood detector **27** for the bathroom floor so that a call centre is alerted if she leaves the bath running. She also has timers which operate lamps and dimmer switches, an iron with a cut-off switch, plus safer versions of ordinary equipment like a kettle with automatic cut-off. All of this has been chosen and installed after a review of her needs in the light of telecare availability and her understanding of how to use it. The assistive technology and telecare doesn't infringe on Paula's privacy and provides security for her and peace of mind for her family. The devices were introduced one at a time so that she became fully familiar with each one before another intervention was introduced.



## Case study 7

James lives alone and his family are concerned for his safety because he has been going out late at night. A sensor **28** is fitted to his door that is activated on exit between midnight and 7am. When this is triggered, a mobile unit is alerted and someone from the unit brings James home. Whilst there may be risk factors associated with anyone being outside after midnight, it was decided that this was an inappropriate and unnecessary risk for James. However, there is no automatic reason why a person with a learning disability should not socialise after midnight. It is important to note that whilst James's family felt he was safer with this form of telecare, it may not necessarily have been his choice.



## Benefits of using telecare

Telecare can, if introduced appropriately, support safety and improve quality of life. Examples from Aspinall (2008)<sup>31</sup> show how independence was developed among residents with a learning disability in a supported group home managed by Home Farm Trust. Here, independent travel became a key focus among residents, assisted by the use of a basic mobile phone, in some cases with built-in GPS. When other forms of telecare were implemented, staff did not have to remind residents to do things around the house so often. Whilst this did not reduce the importance of staff contact, it enabled the individuals to achieve more for themselves.

To work well, telecare needs to meet the specific needs of the person with a learning disability. What is successful for one person will not necessarily work for someone else. Factors to take into account, all of which occur more often among people with learning disabilities, include:

- low or deteriorating cognitive abilities
- low concentration
- limited short-term memory
- poor coordination
- increased likelihood of depression
- reduced communication skills

Key issues include reinforcing wellbeing, individuality and everyday skills. The person's likes, dislikes and preferences must be known, and having access to this information, perhaps through life story work, is essential before any discussion of telecare begins. This will ensure that the person's ambitions and longer term goals can be incorporated into any planned interventions. In the same way, understanding their fears or knowing about previous negative experiences will avoid introducing technology that may cause distress.

Technology can also play a role in addressing the unmet health and screening needs of people with learning disabilities. An example of this kind of intervention used by people who do not have a learning disability is a home blood pressure monitor which sends results to the person's GP practice electronically.

If introduced appropriately, telecare can support safety and improve quality of life.

This type of intervention can be applicable to people with learning disability – providing appropriate adjustments are made and arrangements are in place to ensure informed consent. Telehealth has the potential to record baseline assessments in people with Down's syndrome over the age of 30 as part of screening for dementia. Results can be submitted electronically to track any changes over a period of time.

Telecare can also contribute to health promotion among people with a learning disability. A Scottish project that monitored the lifestyle of people with learning disabilities and encouraged adaptations for a healthier lifestyle was taken a stage further in the USA. Older people in areas of New York received regular phone calls from a personal coach with the aim of increasing their physical activity levels<sup>32</sup>. In a similar project in Canada, people with learning disabilities received face-to-face training, followed by individualised telephone support in conjunction with an exercise DVD which they used at home<sup>33</sup>. Whilst this clearly does not promote community involvement, it addresses areas that many people with a learning disability do not enter into, namely physical activity and education. By promoting activity and exercise, it also tackles the known problem of obesity among some people with a learning disability. Measures such as this may increase a person's confidence sufficiently to encourage them to enrol in an exercise class in the longer term.

### Issues for carers and for care and support staff

The parents of a person with learning disabilities will not necessarily be immediately supportive of the use of technology for their son or daughter, or be willing to monitor its use. Older parents in particular may have had different experiences of caring, often fighting for services at a time when they simply did not exist. As a result, they are often more reluctant to seek help or support<sup>34</sup>, and this can be reflected in a reluctance to work towards more independent living for their son or daughter. They may react negatively to the suggestion of telecare, as it can be seen as the precursor of a reduction in other services, especially staff support. These views must be taken into account before bringing new technology into the family home. Clear, honest explanation, and full information, are essential.

Good planning at an early stage can avoid the need for crisis decisions being made as a parent ages. To be effective, practical support within or outwith the home needs to be part of a long-term care package that is regularly reviewed and incorporates the needs of the person with a learning disability, along with those of their parents or carers. For consistency, respite carers and those offering short breaks need to be aware of any use of technology by the person. Implementing telecare effectively will require clear explanations for carers, as well as for the person with learning disability. This could include providing visual prompts and leaving instructions with the family or carer in appropriate formats such as easy-read, pictorial form or large print.

Carers and care staff also need appropriate training and support in the use of telecare. Although use of mobile phones and the internet is widespread, it should not automatically be assumed that staff or family members will be familiar with them. Staff may have no desire to use these technologies themselves, so may have difficulty incorporating them into their daily work. What may be seen as a reluctance to support a person with a learning disability may in reality be due to feelings of uncertainty about the technology, and these

Carers and care staff also need appropriate training and support in the use of telecare.

It is important that more than one staff or family member is familiar with any technology that is introduced.

feelings need to be acknowledged. These issues can usually be overcome by support and training. In some cases the carer or staff-member may learn alongside the person with a learning disability, which can prove beneficial for both. Training and support for staff are essential, and should form part of personal development plans which will ensure that this area of work is recognised and acknowledged. Additionally, clear lines of accountability and reporting are needed. If necessary, job descriptions and person specifications should be expanded for both existing and new staff to reflect their expanded role.

It is important that more than one staff or family member is familiar with any technology that is introduced. There will normally need to be someone on shift at all times who is familiar with how each piece of equipment works. Equally, call centre staff need to be aware that the person they are responding to has a learning disability and may not communicate clearly. Discussing these issues regularly at team meetings will mean that staff are familiar with the issues they may encounter, rather than becoming stressed when they face a problem or receive a call. This is especially important in organisations where there is a high staff turnover or regular use of agency staff.

When telecare is first introduced, paid staff may have concerns about their job security and be fearful of being replaced by technology. Although the introduction of telecare may open up possibilities for new or different roles, this need not be at the expense of contact time and social interaction with people who have learning disabilities – especially those living alone, for whom loneliness is a very real issue. Instead, routine ‘supervision’ or check visits can be replaced by equipment, freeing up staff time for more worthwhile social interaction. Loneliness has been identified in research<sup>35</sup> as a trigger factor for depression and as being detrimental to independent living. This is an issue that can become more pronounced as the person ages and their needs change. Companionship will still be needed at night for the resident who does not sleep well or who may confuse night and day. What telecare can potentially reduce is the amount of intrusive ‘checking’ that takes place at night, disturbing the person who is sleeping.

### **Potential barriers and how to overcome them**

When considering the use of telecare to support a person with learning disabilities, it is important to ensure that the technology does not introduce an element of control over the person’s behaviour or activities. Instead, telecare should support a move towards independence for people with a learning disability<sup>36</sup>. The decision to introduce telecare should not be based solely on the perceived likelihood of its success or failure. If staff or family members have low expectations of a person’s ability to use telecare, they may subconsciously expect them to fail from the outset. The danger of this self-fulfilling prophecy is that it can lead to an inaccurate assessment of how successful telecare has been. The consequences of this could be serious: for example a flawed assessment could mean that the person is wrongly perceived as not able to cope where they are living. Being prepared to try out telecare with an open mind involves acknowledging risk without taking control away from the person with a learning disability.

The question of choice for the person with a learning disability must also be considered. It is important that they are not given a series of unsatisfactory options to choose from. Equally, choices should not be based on the preferences

of carers or staff (although their support and cooperation is required). Telecare needs to be presented as a realistic option that can be tried out, and is not necessarily a permanent arrangement.

The cost of telecare must be discussed, along with confirmation of who will provide the funding. In practice, the amount of expenditure does not have to be high. For instance, the use of a digital camera to produce a photographic timetable of daily activities or a pictorial staff rota can be a simple but effective aid to independent living.

Many people with learning disabilities now have a mobile phone and use the internet, yet social networking sites are not well used by people with a learning disability. This is due to the complicated registration and signing in process, a lack of clear links to move between pages and the inability to change the size of the text and background colour<sup>37</sup>. If people with learning disabilities are to benefit from these sites they will need additional support to overcome these initial start-up difficulties. Good risk assessment will also consider the potential vulnerability of the individual service user on such sites, and how these risks can be managed appropriately.

### **Introducing telecare – a four-stage procedure**

The following procedure outlines an approach to introducing telecare that is tailored to people who have learning disabilities. It applies the principles set out in the earlier chapters of this book, particularly the importance of carrying out a personalised needs and risk assessment for each person.

#### **Stage 1. Pre-telecare**

- identify the area of difficulty and who this is a difficulty for – the person with a learning disability, their family, carers or service planners
- identify the area of development or need that is being supported and who will benefit from any intervention – the person with a learning disability, their family, carers or service planners. It is important to focus on supporting positive areas of the person's life, rather than focusing on deficits and problems
- record the non-technological adaptations or changes that have been tried prior to telecare. These may include changes to the living space such as lighting, décor, pictorial timetables/instructions, or reductions in noise levels. The review process should also cover staffing issues, and staff should be asked to consider whether their current approach may unwittingly be affecting the behaviour or wellbeing of the person. It is particularly important to think through any areas that are considered to be more problematic for staff than the person with a learning disability and to make sure that the person's needs are being prioritised appropriately
- ensure that social intervention (perhaps in the form of life story work) has begun so that the background, likes, dislikes and future wishes the person can be determined. This work will have long-term benefits, for instance by helping in situations where new staff are unfamiliar with the person, particularly if there is reduced verbal communication

If staff or family members have low expectations of a person's ability to use telecare, they may subconsciously expect them to fail from the outset.

- identify any alternative health monitoring that could be put in place prior to the introduction of telehealth. Options may include an increase in screening, an increase in physical activity, or enrolment in an exercise class, if appropriate
- record where the person lives and who their main caregiver is. Support from this person will be needed to ensure the full benefit of telecare. It is important to establish how long the person will be living in this accommodation, and whether the form of technology proposed can move with them if needed
- consider how the person's health needs are being monitored. As someone ages, changing health needs may require different interventions and regular adaptations which must be tailored to the individual
- record details of any equipment that has already been introduced and who is monitoring this (include single devices that are not connected to an outside source or contact)

Only having looked for and considered alternatives is it appropriate to move on to stage two and introduce first-, second- or third-generation telecare.

### **Stage 2. Introducing telecare**

- confirm and record the method of communication that will be used to discuss telecare with the person who has a learning disability. The same words, signs or pictures should be used consistently. Prior to the discussion, it is essential to build knowledge of the person's preferences and fears. This can be based on life story work (providing it is regularly updated)
- the staff-member discussing telecare needs to be up to date with the options that are available and how they may be implemented. This is essential to ensure that they can clearly explain and discuss the options with the person with a learning disability, other staff and family carer(s)
- identify who will provide instruction or training in the use of telecare, and who will receive this. As part of this process, an audio or pictorial guide or easy-read instruction sheet should be left with the person and their carers. This could take the form of a DVD or CD which can be replayed. Find out whether this already exists for the form of telecare to be introduced, or whether it needs to be recorded by staff. Tools like this will help both family carers and staff-members, including relief and night staff who may not be familiar with the form of telecare being used
- obtain consent to introduce telecare from the person with a learning disability. Consent does not have to be sought or given verbally – pictorial presentation is an option if the information is laid out appropriately, although the process does need to be witnessed and recorded by a carer. It should also be made clear to the person that they can change their mind at any time, and this option should be reinforced at regular reviews
- obtain consent from someone who is familiar with the person and with their non-verbal communication methods, if appropriate
- if consent is refused then it must be clear that this reflects the person's own decision, rather than the influence of family, friends or staff. The implications of refusing consent – such as the risk of the bathroom flooding – should be discussed with the person

- confirm the form of telecare that has been agreed to, how regularly its use will be reviewed, and by whom. The device(s) may need to be adapted as the person get older and their health needs change
- make sure that it is clear who will pay for the telecare and that all hidden costs, such as additional electricity or telephone bills, are calculated
- decide how often to hold review meetings and who will be involved in these

### Stage 3. Implementing telecare

- the form of telecare introduced needs to be understood by the person with learning disabilities and their carers and should not be too complex. It needs to be clear who is responsible for maintenance and upkeep
- only one new intervention should be implemented at a time to allow the person and their carers to become familiar with it. One device may be enough, but if others are going to be introduced the full procedure (above) should be repeated to make sure it is clear why the device is being used and who will benefit
- if the number of visits by staff or health professionals to a person's home is to be reduced as a result of telecare or telehealth, service planners should make sure that staff are able to compensate for this with social visits. This is not for surveillance or monitoring, but to provide companionship and social contact, and to prevent loneliness and isolation. Telecare should not replace face-to-face contact, but instead allow a shift of emphasis from practical help to social support
- it is important to regularly remind staff and family members that the reason for introducing telecare is it to increase safety, improve wellbeing, and/or support daily living. By being clear about this remit, changes can be made as necessary

Regular reviews are essential to ensure that telecare continues to provide appropriate support.

### Stage 4. Reviewing telecare

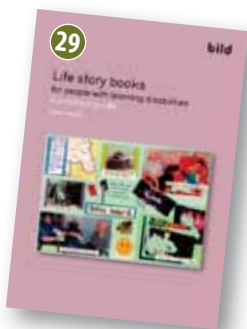
Regular reviews are essential to ensure that telecare is continuing to provide appropriate support.

- be clear about what the evaluation process involves. This means carrying out regular reviews that involve the person with a learning disability, along with others who provide care for them. A record should be kept of review meetings so that successful use of telecare can be documented and the impact of any changes noted
- although each implementation is an individual process and may not result in the same outcome for someone else, it is still important to record what worked and what didn't. This will help staff or carers understand what has been tried and can flag up potential issues during future implementations

## An example of introducing telecare in practice

David is 51 and has a learning disability. He lives in a single room in a shared house with two friends and has been waking at night, possibly as a result of seizures which started four months ago. Staff check his room every half hour at night, often disturbing him further. This leaves him tired and bad-tempered during the day. David enjoys gardening and travels by bus to the local garden centre, where he is a volunteer two days a week. Twice recently he has got off the bus at the wrong stop. His voluntary work is very important to him, as is living semi-independently. He has friends there and has known many of the staff for years. Until five months ago when he died suddenly, David's brother Robert visited every weekend.

### Stage 1. Pre-telecare



- with David's consent, grief counselling was sought and a life story book 29 developed with staff to encourage him to talk about and remember his brother
- a card was made on the computer to hand to the bus driver and this helped ensure that David got off at the right stop when travelling to the garden centre. David also started carrying a large-buttoned mobile phone with preset numbers which meant he could phone the group home or the garden centre if he got lost. Each of the changes described was introduced separately, as outlined by the procedure above
- it was important to clarify who would benefit from these interventions, with David's needs being seen as most important. However, there were also benefits for staff at the group home and the garden centre
- David's key worker and her manager attended training in the use of telecare. This was discussed in supervision and formed part of an agreed training and development programme. Information gained from the training was passed to the staff team at the team meeting

### Stage 2. Introducing telecare

- staff spoke with David about whether the interventions were meeting all his needs. There was still the outstanding issue of disturbance at night, so forms of telecare were explored to support David in this area. The option selected (because it was considered to be the least restrictive available) was a seizure monitor 30. This was used at night and reduced the amount of night-time checking that was required. David was given verbal and pictorial information about how the pad worked, along with a demonstration by staff
- as with the other interventions, it was important to clarify who would benefit from introducing the seizure monitor. It was found that David's quality of life improved as a result of him sleeping better at night. Collectively, the interventions enabled his wishes to be met as he had expressed a desire to stay in his group home and continue volunteering at the garden centre
- four other staff, including night staff, attended training in the use of telecare





### **Stage 3. Implementing telecare**

- David's key worker took the lead role in monitoring the telecare used. She made a note in the staff diary that he should be asked if his mobile phone was charged and in credit every few days. Staff were reminded that introducing the technology was not about control. For example, David could still choose to get up in the night if he was unable to sleep, and attempts would not be made to restrict his movements

### **Stage 4. Reviewing telecare**

- had David not given his consent to some or all of the changes, the possible outcomes or consequences would have been explained to him, along with the option to change his mind later. He knew that he could try a solution without having to keep it in place if he wasn't happy with it. There may have been a greater risk to David if some or all of the changes weren't made
- reviews took place every three months and involved David, staff from the group home and staff from the garden centre. The meetings were formal, with notes kept so that David and everyone involved in his care had a record of any changes that were agreed. Informal monitoring also took place on an ongoing basis. This led staff to realise that David was not always taking his card on the bus with him because he had got to know the regular driver, who always reminded him when to get off. This became problematic when another driver was on duty. When staff realised what was happening, David's key worker put a pictorial sign on the back of his door to ask him if he had his card with him before he left for the bus. He then had the option of using it if there was a different bus driver

There are no right or wrong answers in a scenario such as David's, as responses will differ between individuals. What is important is being able to justify the decisions that have been made. With the inclusion of telecare in his support plan, David was able to keep his volunteer placement and continue travelling independently. His social and emotional needs were also addressed.

## 5: Training programme

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This section contains content and a suggested timetable for a one-day training programme on how telecare can contribute to the care and support of people with a learning disability. It may also provide a basis for a longer programme for specialist assessors or 'telecare champions' if combined with 'shadowing' experiences and visits to a control centre, response team, and contact with service users already experienced in telecare. Similarly, it may be of value to course leaders of qualifying programmes for social workers, occupational therapists and community nurses.

It is an outline programme which skilled trainers will need to adapt to the particular training needs and circumstances of local groups.

### Aim

To support participants in the development of their knowledge, skills and understanding required to introduce telecare into individualised care packages.

### Objectives

- to learn how telecare can contribute to the support of people with a learning disability and their carers
- to develop practice in needs and risk assessment, and care planning, so as to maximise the benefits of telecare
- to increase knowledge of the legal and ethical framework for good practice
- to understand the wider policy and strategic context for telecare

### Timetable

#### 9.00 Welcome and introductions

- domestic arrangements
- discuss agenda and clarify expectations of the course. Refer to the aims and objectives to confirm what the course can and cannot provide. Invite participants to discuss, briefly, with each other, their current knowledge and understanding of telecare, their perceptions and anxieties about technology, their expectations of the day, and their individual training needs

### 9.30 Definitions of telecare and telehealth

This could be a 'teaching' session with a presentation and handout based on the definitions provided in the introduction to this book.

Key learning points are:

- the meaning of terms such as telecare, telehealth, telehealthcare and an introduction to the 'generations' of telecare
- the lack of commonly accepted standard definitions, and the extent to which terms are interchangeable, and changing
- the speed with which technology is developing in all areas of our lives
- the effect of this on service user and carer expectations

In this session it will also be important to remind participants about the nature and impact of different sorts of learning disability, and so begin to explore the ways in which technology can support people with different conditions. Assuming that participants will already be working in the field of learning disability, the key learning points will include:

- being aware that the successful introduction of telecare depends on understanding the individual nature of a learning disability
- being able to develop and use specialist communications skills if the learning disability has affected speech as well as comprehension
- taking a person-centred approach to care and support and encouraging higher expectations among the family and carers of people with learning disabilities. This includes developing a proactive approach which engages the person in meaningful and enjoyable activities
- being open to new and changing ways of providing support

Gather together any thoughts and initial reactions at this stage without looking for conclusive ideas. Some of the definitions may be new to participants, and time is available to ask questions about these throughout the day. Reassure participants that they will have the opportunity to apply these to practice later.

### 10.15 How can telecare help support people with a disability?

This should be an opportunity for participants to see pictures of, and, if possible, actually touch and feel equipment. It is important to explain the kind of support needs for which pieces of equipment may be useful, and to talk through examples of equipment which may be in development but not yet available.

Local providers and suppliers may offer to put on a display of equipment, at no charge. If there is a local 'smart house' it may be possible to hold the training session there – or to organise a visit at the end of the day or during the lunch break.

Ask the group to look at the illustrations of equipment and share their ideas about each item's uses and limitations. Participants may have additional valid suggestions about uses and limitations based on their own experiences. Ask the group to split into pairs and think about a person they know who may benefit from some of these adaptations or interventions, along with someone who would be unlikely to benefit from them.

### 10.45 Break

### **11.00 Case studies – telecare in practice**

In this session, participants will look at a variety of different scenarios in pairs and think about what equipment would be useful. It is also important that they think through the implications – for example:

- what is the need that is to be met (the importance of careful assessment; avoiding simplistic solutions; not ‘just giving out bits of kit’)
- the different perspectives of the service user, their family and support staff
- differing attitudes to risk
- how telecare can supplement other kinds of support but is not intended to replace them
- the importance of maximising levels of independence and retaining personal skills
- promoting proactive self-management of long-term health conditions or learning disabilities
- encouraging/enabling individuals to remain in their own homes/communities for as long as is safely possible
- reducing unnecessary movement to alternative forms of accommodation, such as nursing homes, care homes and hospitals
- fostering a feeling of security for individuals and their families
- improving quality of life
- providing greater choice

Ideally, participants will share their own experience and ‘cases’ with colleagues. This book also contains some case studies which can be used as an alternative, or in conjunction with participants’ own experience. The trainer will need to decide how best to use some or all of these – perhaps giving the initial scenario first, then comparing the solution suggested in the book with the group-members’ own ideas.

### **12.00 The importance of good assessment**

Bring participants back together as a single group and compare the ideas that emerged in the previous session. Encourage debate about how telecare contributed to the support of the individuals in the case studies in the following ways:

- draw out the importance of good assessment. Refer to the section on assessment in this book. If necessary, develop a handout or use an example of a local assessment tool
- make sure risk is considered, and well as need
- highlight the differing concerns and benefits as seen from different points of view
- bring any difficult issues into the open, such as staff reluctance or how carer concerns should be addressed
- highlight what the problem is and who the telecare is intended for. Are there consent issues, or differing perspectives on risk, need, capacity or consent?

## **13.00 Lunch**

### **14.00 Telecare may be the solution ... but is it 'right'?**

This is an opportunity to discuss with participants the rights and wrongs of using telecare, looked at from their own perspective, as well as their employer's and professional perspectives. Chapters 2 (Assessment) and 3 (Principles, rights and ethics) may provide the basis for a short introductory talk. Alternatively, this could be an interactive session in which the following kinds of questions are posed:

- telecare can involve the monitoring of people's private lives. Is that 'right'?
- some equipment restricts people's freedom to do as they want or go where they want in order to 'protect' them. What is the right balance between risk and protection and how do we achieve it?
- telecare can be used to support a 'normal' lifestyle – getting up in the morning, going out during the day and going to bed at night. Is telecare being used to 'impose' a conventional lifestyle?

Stress that people with a learning disability should only have their movement restricted or monitored with permission, and where this complies with the law and care regulations. Discuss what permission means where there is significant cognitive impairment and talk through what the law dictates in this area. These issues can be discussed in the context of the case studies from the previous session.

Participants need to be clear about the legal constraints on this (and any other) part of their support service. They have a responsibility to make decisions that are both ethically defensible and legal. An approach based on individual assessed needs will always present ethical dilemmas which need to be resolved.

### **15.00 Policies, procedures, and strategy to support the use of telecare**

This session provides an opportunity for participants to explore and gain a better understanding of local policy and procedures. It should include discussion of local assessment tools to ensure that participants understand when and how telecare can be introduced into the assessment process. Local procedures for accessing telecare, as well as for installation, testing and responding to call-outs, should be discussed and explained, along with charging policies and budgets.

It may also be useful to discuss local strategy. How does the use of telecare fit with local joint strategies for people with learning disabilities? If time is available, it will be useful to look at the national strategy too and discuss how telecare can contribute to national policy goals such as Shifting the Balance of Care. (Resources are available on the National Telecare Development Programme website – [www.jitscotland.org.uk/action-areas/telecare-in-scotland/](http://www.jitscotland.org.uk/action-areas/telecare-in-scotland/))

### **Alternative**

If the programme is for participants from different agencies and localities, or in qualifying college-based programmes, the following alternative training session, based on the 'model' procedure (see page 27), can be used.

### **15.00 Introducing telecare successfully – a four-stage approach**

On pages 27–29 of this book a four-stage approach is outlined for introducing telecare to someone with a learning disability. This is followed by a case study that follows the four-stage model. Ask the group to discuss the procedure and how it worked for David. Draw out some of the following points:

- what was the outcome for David? Does the group think that any other environmental or staffing options could have been used in addition to other forms of telecare?
- how could the people caring for David be confident that each intervention worked and represented the right decision? At this stage you should emphasise the importance of the review process, and of everyone involved in assessing an individual understanding how it works
- what is their view of the consent and ethical issues encountered?

Discuss the advantages and disadvantages of the procedure from different perspectives. Talk about whether it is appropriate to replace face-to-face staff contact (either during the day or at night) with a telecare solution. Emphasise the importance of social contact and the potential danger of increased isolation if staff provide less face-to-face support. Although fewer overnight checks are needed if a seizure monitor is used, this does not necessarily mean that waking night staff are no longer needed. Will David's health needs change as he gets older? If so, how?

### **16.15 Conclusions and evaluation**

Ask the group if the discussions they have had during the afternoon have influenced the way they would now approach the case studies introduced earlier in the day. Do they now feel more confident about making a recommendation and supporting a person with a learning disability to make an informed choice about telecare?

Summarise and ask what the participants will take away from the day. The discussion could include areas of new technology and the potential for the future use of telecare and telehealth as a way of supporting people with a learning disability.

## Additional resources\*

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For further information about telecare and the National Development Programme in Scotland, please contact the Joint Improvement Team via their website:

<http://www.jitscotland.org.uk/action-areas/telecare-in-scotland/>

The website for the equivalent programme in England is:

<http://www.dhcarenetworks.org.uk/independentlivingchoices/telecare/>

### Other websites

Information and general advice from the Disabled Living Foundation:

<http://www.livingmadeeasy.org.uk/telecare-167/>

Consumer reports on telecare equipment:

[http://www.ricability.org.uk/consumer\\_reports/at\\_home/](http://www.ricability.org.uk/consumer_reports/at_home/)

Home Farm Trust is a national charity supporting people with learning disabilities and their families. For more information about what they call 'personalised technology' email [personalisedtechnology@hft.org.uk](mailto:personalisedtechnology@hft.org.uk) or visit [http://www.hft.org.uk/What\\_we\\_do/Assistive\\_technology](http://www.hft.org.uk/What_we_do/Assistive_technology)

The AT Dementia website brings together information about assistive technology that has the potential to support the independence and leisure opportunities of people with dementia: <http://www.atdementia.org.uk/>

Information on assistive technology for people with dementia:

<http://www.atdementia.org.uk>

Telecare Services Association (TSA):

<http://www.telecare.org.uk>

Social Care Institute for Excellence – Dementia Gateway. This section of the website looks at the use of technology:

<http://www.scie.org.uk/publications/dementia/environment/assistive.asp>

Centre for Usable Home Technology:

<http://www.cuhtec.org.uk/>

Centre for Accessible Environments:

<http://www.cae.org.uk/>

Enable:

<http://www.enableproject.org/>

Dementia Services Development Centre:

<http://www.dementia.stir.ac.uk>

### DVDs

Telecare – supporting Scotland: a different approach. DVD which includes seven 'digital stories' illustrating, in the words of users and carers, the impact of telecare. Available through

<http://www.jitscotland.org.uk/action-areas/telecare-in-scotland/>

Telehealth in Action. Scottish Centre for Telehealth:

<http://www.sct.scot.nhs.uk>

## Publications

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\*All websites accessed 24.02.10



## Supplier contact details

The images of equipment featured in this book represent a small subsection of the range currently available. The contact details below have been included to assist purchasers in assessing what is available from whom, but in many cases the same device is available from more than one supplier. The publishers in no way endorse any particular supplier or product. The lack of inclusion of a particular product does not imply that it is inferior to any device featured. Purchasers are responsible for researching the full range of products available and reaching their own conclusions about what is most suitable for them or their clients.

<p>BILD <b>29</b>          Campion House          Green Street          Kidderminster          DY10 1JL          Tel: 01562 723010          www.bild.org.uk</p>	<p>Buddi Ltd <b>21</b>          53 Ovington Street          London          SW3 2JA          Tel: 0871 423 8756          www.buddi.co.uk</p>
<p><b>5 10 12 15</b>          Chubb Community Care          Shadsworth Road          Blackburn          BB1 2PR          Tel: 01254 688774          www.chubbcommunitycare.co.uk</p>	<p>Halliday James Ltd <b>19 20</b>          Ezekiel House          Ezekiel Lane          Willenhall          WV12 5QU          Tel: 0121 661 6806          www.hallidayjames.com</p>
<p>Pivotell Ltd <b>14 25</b>          PO Box 108          Saffron Walden          CB11 4WX          Tel: 01799 550979          www.pivotell.co.uk</p>	<p>Sensorium Ltd <b>22 24</b>          9 Nethertown Broad Street          Dunfermline          KY12 7DS          Tel: 01383 720600          www.sensorium.co.uk</p>
<p>RSL Steeper Ltd <b>26</b>          Unit 6, Hunslet Trading Estate          Severn Road          Leeds          LS10 1BL          Tel: 0113 207 0432          www.rslsteeper.com</p>	<p>Tynetec Ltd <b>2 7 8</b>          Cowley Road          Blyth Riverside Business Park          Blyth          NE24 5TF          Tel: 01670 352371          www.tynetec.co.uk</p>
<p>Tunstall Healthcare (UK) Ltd <b>1 3 4 6 9 11 13 16 17 18 23 27 28 30</b>          Whitley Lodge          Whitley Bridge          DN14 0HR          Tel: 01977 661234          www.tunstallhealth.com</p>	

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# Telecare and learning disability

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Using telecare effectively in the support of  
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