Gadgets, Gizmos and Gaining Independence

ASSISTIVE TECHNOLOGY

and

People with Learning Disabilities

Gadgets, Gizmos and Gaining Independence

Assistive Technology and People with Learning Disabilities

Contents

Foreword

by Ivan Lewis MP, Minister for Care Services

Advances in our understanding and the developing application of assistive technologies now enable people with a range of care and support needs to take greater control of their lives, access the support they want and the services they need. There is no doubt that new and emerging technologies offer older people and other vulnerable adults an opportunity to enhance their lives and to develop solutions that promote independence.

I am delighted to provide a foreword for this report. It demonstrates the extent to which new technology can contribute to making a radical shift in the way people with learning disabilities can benefit from assistive technologies at home, in care and support settings. It also shows how far thinking has progressed, incorporating assistive technology in the development of client-centred housing and provision of care, supporting choices for people with learning disabilities.

This report reflects the policy and practice ambitions of commissioners, providers and, above all, users of services. It also complements and supports the objectives of the White Paper, *Our health, our care, our say: a new direction for community services* and the recent guidance on the development of assistive technologies and the Preventative Technology Grant, *Building Telecare in England*. The report is therefore timely as it makes crucial links to the aspirations and demands of people with learning disabilities and how technologies can support social care in the 21st century.

Summary

This report says:

- What Assistive Technology is.
- Where to get Assistive Technology.
- How it can help people with a learning disability.
- How much it costs and where to get money to pay for it.

Assistive Technology is a range of gadgets that can help people be more independent and do things for themselves.

This report has been written to help more people with a learning disability use Assistive Technology.

This report is about electronic Assistive Technology that is run by electricity or battery. This is sometimes called telecare and telemedicine.

This report also talks about computers and telephones that can help people live more independently.

Types of Electronic Assistive Technology

Telecare – gadgets that can sense what is happening in your home and call for support from outside of your home if there is a problem. Also gadgets that you can use to call someone from outside of your home for help.

Telemedicine – gadgets that a person wears that can check a person's health and tell someone outside of the home if there is a problem.
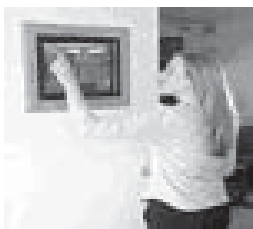
Smart Homes – homes that have computers that can do things like make doors and curtains open and close and remind people to lock doors and windows when they go out.

Communication Aids – a large range of computers, programmes and telephones that help people to communicate more easily.

Most Assistive Technology is used by older people and people with a physical disability. There are not many people with a learning disability who use it.
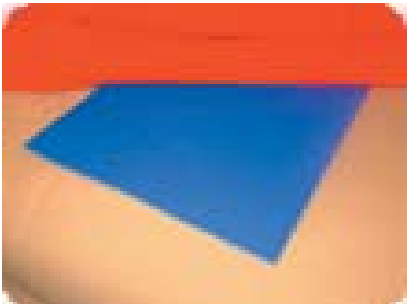
The reason that not many people with a learning disability use Assistive Technology is that most staff who work with them, like care providers, care managers and Occupational Therapists do not know much about it.

There are some support providers and councils who help people with a learning disability to use Assistive Technology. We found out by talking to them that it could help people with a learning disability to live more independently.

Some ways to make sure that more people with a learning disability can use Assistive Technology

■ Assistive Technology is used by older people who live in sheltered housing and extra care housing and is usually built into the housing from the start. This should be the same for supported housing schemes that are developed for people with a learning disability.

■ All people with a Learning Disability who have a Community Care Assessment should also be assessed to see how Assistive Technology could be part of their support package.

■ Assistive Technology can be used as a way of providing extra support to people with a learning disability who live in their family home and help carers.

■ Support and care providers could introduce and test Assistive Technology to improve the way they provide support to people with a learning disability.

■ Make sure that people, their families and professionals know about Assistive Technology and how to pay for it.

Gadgets	How you can use them
	This pendant is worn around the neck or on the wrist. In an emergency situation the button can be pressed to call for help from someone that knows about the type of help you need.
	This movement detector can tell if you are moving around your house or not. If your movement is different to normal, like if you have not moved around for a long time, someone will call to check to see if you are OK or not and get help if you need it.
	This bogus caller sensor is a button by the door that you can use if you are worried about a person at your front door. It will call out someone to help you.
	This bed occupancy sensor can tell when you go to bed and get up. If you are in or out of bed at an unusual time it can contact someone to find out if you are OK or not and get help if you need it. This might be good if you fall out of bed.
	This Carbon Monoxide (CO) sensor can tell if you have dangerous levels of CO from a boiler or fire. It can call someone to help.
	This mat can tell if you are having an epileptic seizure in bed and call for help.

Gadgets	How you can use them
	This fall alarm is usually worn on a belt or waistband and can tell when you fall and call for help.
	This flood detector can tell if taps have been left on and there might be a flood. It sets off an alarm or tells someone who can help.
	This gas detector can tell if there is a gas leak or the gas has been left on the cooker. It connects to a valve that can turn off your gas.
	This medication dispenser reminds you to take your pills when you need to. f you do not take them it calls someone who checks to see if you are OK.
	This mobile phone is for people who find it difficult to use ordinary mobile phones. It has three buttons to call three different numbers and if the red button is pressed twice, it calls emergency services. The phone can also remind you about things like the time to leave work, get up, or catch a bus.
	There are a lot of gadgets and programmes that can make using a computer easier, especially for people who do not read and write.

Chapter 1   Introducing Assistive Technology

1.1 Purpose

The reason for producing this report is to extend the use of Assistive Technology (AT) by people with learning disabilities. It does this by:

- Explaining in simple terms what AT is available and what it does.
- Where to get AT and how to put it in place with an individual.
- What it costs and what the benefits and pay back are.
- What the results of using AT can be.

The aim is first, to help those working directly with people with a learning disability use AT in practice. Second, to act as a catalyst to get AT on the agenda for organisations involved in supporting people with learning disabilities.

1.2 Why is the work necessary?

It is observable that most of the emphasis on promoting AT has been in its use by older or physically disabled people. In principle many of the devices now widely available could benefit people with a learning disability, but it is hard to find more than experimental examples.

National policy is to enable as many people with a learning disability as want it to have their own property; to live as independent a life as possible; and exercise as much control and choice over everyday decisions and lifestyle as they reasonably can. AT is helping older people do just this.

However, there are differences. Most older and many physically disabled people will have their own homes. Three out of four of the population in fact own their own home when they retire. The task is to use AT to maintain or enhance the ability to carry on living an independent life. For many people with a learning disability it is different. They may have lived in a more institutional setting or at home with parents or another relative (more than half of all people with a learning disability are still supported by relatives, in the relative's home). The tasks here may be different:

- To support an independent life for the first time following a move from an institution, or relative's home.
- To help or relieve carers so they are better able to continue to provide support.
- To provide more reliable support.
- To provide support in a less intrusive way.

One of the reasons put forward for the slow progress in using AT to support people with learning disabilities is simple lack of knowledge by those who need it most – care managers, parents, care workers, commissioners, housing staff, as well of course by those with a disability. The aim of this report is to give real, practical, understandable information in plain English.

> ## Reasons for limited use of AT by people with a learning disability
>
> The practitioners interviewed in this study offered the following additional reasons for the slow progress in using AT to support people with learning disabilities:
>
> - Entrenched attitudes.
> - Assumptions that telecare will not work for people with a learning disability
> - Lack of knowledge of possibilities.
> - Lack of experience to specify, buy, assess, install equipment.
> - Support staff, care managers and care provider organisations were 'people' orientated and not technically competent or orientated; "*the answer is always more staff*".
> - Numerous small care providers characterise the field. Individually they lack resources to investigate and build expertise.
> - Uncertain funding or no capital funding for larger equipment.
> - Lack of knowledge in Integrated Community Equipment Centres of ability to offer AT; also approach of loaning equipment as opposed to viewing as capital investment for environmental control equipment.
> - Some manufacturers are not interested in bespoke solutions or smaller learning disability market.
> - Occupational Therapists (OTs) are often gate keepers to funding. Too few available and lack of specialist expertise.
> - Ethical concerns in relation to some monitoring devices where understanding by resident is very limited.

A new Preventative Technology Grant from the Department of Health became available to all local authorities from April 2006. This is to pump prime and promote the use of AT. This study should help decision makers to include people with learning disabilities in new services and plans.

Appendix 1 provides more information on this grant.

1.3 When we say Assistive Technology what are we talking about?

A can opener is a bit of technology that assists you to open a tin. Using the handle of a spoon to lever off the lids of ring pull cans is even more basic technology. AT can have a very wide meaning:

"An umbrella term for any device or system that allows an individual to perform a task they would otherwise be unable to do or increases the ease and safety with which the task can be performed"

Source: 'A glossary of terms for community healthcare and services for older people' WHO, 2004

"Any item, piece of equipment, product or system, whether acquired commercially, off the shelf, modified or customised, that is used to increase, maintain or improve functional capabilities of individuals with cognitive, physical or communication difficulties."

Source: 'Astrid: a guide to using technology with dementia care' Marshall 2000

It can help support independence in broad terms by:

- Helping to prevent accidents.
- Creating a safer environment.
- Enabling independence and quality of life.
- Reducing the effects of disability by giving greater control.
- Assisting or relieving carers.

For the purposes of this work the focus is on technology that can extend independent, supported living in three main ways:

- Through managing risks better using 'telecare' or 'telemedicine'.
- Assisting communications.
- Offering better control of facilities in the home, 'environmental controls'.

We are also talking about electronic rather than simply mechanical technology.

1.4 What we have done – method

The work has been undertaken by the Housing and Support Partnership on behalf of Advance with the aid of a Section 64 Grant from the Department of Health (DH). In completing this guide we have:

- Brought together a small group of interested organisations including housing associations, local authority, and care provider representatives along with the Department of Health. These formed a steering group for the study.
- Researched the products commonly offered by manufacturers and used to help older people remain independent which might be relevant to people with learning disabilities.
- Investigated through a series of visits and interviews the actual experience of people with learning disabilities and care providers in using Assistive Technology.
- Made enquiries about the use of Assistive Technology in America and Australia.
- Held a consultative Conference to discuss action on Assistive Technology.

These five elements are the basis of this guide.

1.5 Assistive Technology for the terrified: terms, devices and jargon

The terminology is just one aspect of what gets in the way of more wide spread use of AT by people with learning disabilities. Positions can go from:

"I am a social worker, what do I know about all this electrical stuff?"
(Social Worker)

to…
"I was a social worker but Peter showed me how to set the equipment up in 20 minutes"
(Director of Care Provider, ex Social Worker)

We explain here what AT as a general description embraces and how things work in non-technical terms.

1.6 Telecare

Telecare is bits of technology that help provide an element of care or support.

The starting point of what we now think of as the telecare part of the AT 'family' is 'community alarms'. Forty years ago when sheltered housing for older people was first developed a defining feature became an alarm system. People pulled a cord and this triggered an alarm. At the crudest level this caused a bell to sound or a light to flash on the wall outside and the theory was that neighbours would respond to the emergency.

At a slightly more sophisticated level the alarm alerted an on site warden who answered the call. There have been three substantial developments since then.

1   Control Centres – basically a call centre – have been set up linked to the individual alarms. These monitor alarms 24 hours a day and can call whatever emergency or care assistance is required. Details of each person connected to the call centre are instantly available, and the operators have a list of nominated people to summon. This might be a neighbour or relative but, during working hours at least, is likely to be staff either on site or as part of a mobile response service.

Alarms are linked to central control via the telephone network and the control centres are computerised. The technology evolved so operators can have two way conversations with whoever has pulled the alarm so that if they can speak they can explain what the problem is. It is also possible for the operators to carry out various tasks remotely – for example open the outside door of a scheme to the postman.

2   Dispersed alarms – the second significant change over the last ten years has been the development of dispersed alarms. The original sheltered alarm systems were 'hard-wired'; that is, using cables run around a building connecting all the alarm services together. Alarms were largely restricted to sheltered schemes, care homes, hospitals and similar institutions. This is no longer the case. Dispersed alarms are 'boxes' (base units) that sit under the phone (or incorporate a phone) that can dial into a central control monitoring service in just the same way as an old hard-wired alarm (or call staff on site directly). They have the same two-way speech facility.

The implication is that anyone, wherever they live, can have a community alarm service. You no longer have to live in a 'special' building, but can have a dispersed alarm in any dwelling.

3   Sensors – the final critical step has been the growth of a huge array of sensors that can be connected to a dispersed alarm. In principle many of these 'devices' are commonplace technology like smoke alarms or burglar alarms. What they do is monitor (i.e. measure what is going on) the 'environment' – the space in a house or around a person.

They do this in a variety of ways, but a burglar alarm is a good example. Typically these use infrared beams. When a beam is interrupted an alarm is triggered. This principle has many applications and 'passive infrared' detectors are widely used in telecare packages. Manufacturers shorten this to 'PIR' – a bit of the jargon.

The step on from the basic burglar alarm analogy is that the dispersed alarm 'box' can consistently monitor literally dozens of devices (different sensors). It sends a signal back to Central Control and if an unusual or unacceptable event happens an alarm is automatically triggered – for example a room is too hot or too cold, smoke is detected, a door is opened

after a certain pre-determined time, a flood on the kitchen floor – and so on. Finally, some sensors can monitor a person rather than the environment, for example a fall detector.

Note that we have two different possibilities for an alarm:

1   An individual can directly summon help by pressing a button, pulling a chord or in some other **active way.**

> ### Example - Joanne
>
>
>
> Joanne uses a wristband pager to alert on site staff when she needs support in her flat.

2   Help can be called without the individual doing anything directly – **passive.**

> ### Example - Stephen
>
> When Stephen opens his door to leave his house, a sensor triggers a call to the staff pager so that he can be supported when leaving his home.

It is the latter, passive detector that is at the heart of much environmental monitoring. Telecare is then an array of sensors and alarms linked (usually via telephone lines) to a system for monitoring wellbeing. An alarm can be triggered without the person doing anything, and this is what distinguishes modern telecare from traditional community alarms.

There are various definitions around to give a clear focus.

> ### A definition of telecare
>
> "Telecare is provided at a distance using information and communication technology (ICT). Telecare is the continuous, automatic and remote monitoring of real time emergencies and lifestyle changes over time in order to manage the risks associated with independent living."
>
> *Source: Getting Started – Telecare, ICES/DH, 2005*

Telecare devices can:

■   Anticipate problems, for example a special wristband (a characteristic of telemedicine) which can monitor a person's physical state, possibly providing early warning of risks to health.
■   Prevent problems, for example turning lights on when a person gets out of bed, preventing a fall.
■   Mitigate harm, for example sends an alert to staff or Central Control if someone leaves (or enters) a building (or a room) after a certain time.

1.7 What else do I need to know about telecare?

- Sensors and a dispersed alarm do not need to be linked together by wires. Many of the devices 'talk' to each other using radio signals. This means they are easy to install wherever necessary – including in someone's own house or flat.
- The alarm can be programmed and altered remotely by an operator at Central Control once set up. So if programmed to call a care assistant, if the resident has not opened the fridge door by 8.00 am this can easily be re-set to a different time or turned off while someone is away on holiday.
- Setting up a package of equipment may require more specialist knowledge but is not too difficult; it involves installing the equipment and then initial setting up, sometimes using a hand held computer device. Equipment which uses motors (like door openers or window openers) is more complex to install and probably will require a specialist.
- Many ordinary domestic appliances already have 'chips' or small computers in them. They can be linked together or controlled remotely.
- Signals controlling devices can sometimes be sent along ordinary electrical wiring. In addition, special replacement plugs can be fitted which allow remote control of electrical appliances. Both these features are used in SMART homes (explained later).
- Devices from different manufacturers that do the same job, such as detect a fall or an epileptic episode, may work in technically slightly different ways. Sometimes it helps to understand how a particular product does its job in order to find the one most suited to the individual. Alternatively, it may be necessary to test several apparently similar products to find the one that works the best for an individual, or tune the device to the individual by trial and error.
- Just because a piece of AT is available it is not necessarily the best way of meeting a need. Preventing a problem, rather than knowing a problem has occurred, is generally a better approach. One example of both these points in the course of this project was flood detectors. These are cheap and easy to install anywhere. However, a simple and equally cheap (mechanical) plug replacement will prevent a bath or sink overflowing. It does not however turn the water off! In one case study example both kitchens and bathrooms were fitted with floor drains so that flooding would cause minimal damage.
- OTs should be good sources of advice on the range of products available to meet particular needs. However, feedback from practitioners in this study suggests that even more specialist OTs may lack knowledge of products and how they work. Also there was a shortage of OTs, making delay commonplace.
- If starting with a new building it is now less necessary to think about wiring in telecare equipment and alarms. It may however still be important to think about what developers call the 'infrastructure'. Mainly, this will be putting sufficient power points in the right place, e.g. bottom left hand of a window if a window opener is to be fitted. A broadband connection is also necessary for some applications.

The other elements of AT we describe in a more limited way.

1.8 Telemedicine

In concrete terms telemedicine involves an individual wearing a device, typically like a wrist watch. This sends signals about the person's physical wellbeing to a health expert based some distance away. An example of a more precise definition is:

"Telemedicine is the remote exchange of physiological data between a patient at home and medical staff at hospital to assist in diagnosis and monitoring (this could include support for

people with lung function problems, diabetes etc). It includes (amongst other things) a home unit to measure and monitor temperature, blood pressure and other vital signs for clinical review at a remote location (for example, a hospital site) using phone lines or wireless technology."

Source: Curry R G, Trejo Tinoco M, Wardle D (July 2003) 'Telecare: Using Information and Communication Technology to Support Independent Living by Older, Disabled and Vulnerable People' available at www.icesdoh.org/article.asp?Topic=89

In the course of our project we found only a few care providers beginning to experiment with telemedicine for individuals with a learning disability.

1.9 Smart Homes

Pioneered by the Joseph Rowntree Foundation, SMART Homes involve putting an array of equipment into an ordinary house to make it easier for a physically disabled person to live independently. The equipment will for example:

- Open and close doors, open curtains electronically.
- Allow the occupier to remotely open the front door.
- See who is at the front door on the television via a camera link.
- Include an array of environmental monitoring as described above in referring to dispersed alarms and sensors.

The permutations are considerable and in more comprehensive examples can include:

- Voice activated phones and other equipment.
- Remote (or computer) operation of all electrical equipment which could extend to turning on the cooker while driving home.
- Variable height worktops, storage cupboards or shelving systems in kitchens and elsewhere.

The key to understanding the concept of a SMART home is to see that in essence there are three elements connected together which can be almost infinitely extended:

1   *A motor* – to open and close doors, raise or lower a shelf.
2   *A switch* – these come in innumerable forms: a round electric switch; a button; something you breathe on; a footpad; joystick; breaking a beam; touch screen; or voice activation.
3   *A computer* (or possibly several) – which sits in the middle and controls the switches as programmed.

It is quite useful to think of a 'switch' being central to much of AT, including telecare. It is just that switches come in many guises. The computer is itself a switch. The term 'SMART' is used because what makes the house different is that a range of devices and equipment are linked together (via the computer system) rather than separate. So for example triggering a burglar alarm can turn on the lights in the house and close doors or windows. Pressing the front door bell turns the television on showing who is at the door, or triggers a message, or flashes the house lights.

Case Study

Elmington supported living scheme

This is two new-build, three-bedroom houses. One is designed to mobility standards for a tenant who is a wheelchair user and the other is built to Lifetime Homes Standard. There are six tenants with learning disabilities who receive support seven days a week from eight staff, including sleeping night cover.

The building was hard-wired. PIRs are used to detect activity, a video door entry system for security, smoke detectors, window and door sensors and help boxes in the bathrooms were fitted. Transmitters link the system to pagers held by the carers on site. Sensorium and SRS Technology installed a system that monitors some activity and daily living patterns, then reminds service users, when appropriate, to do certain things. This level of choice and control is achieved through a system of 'logic controllers' and transmitters, strategically placed sensors, and the use of clever software. The modules activated in Elmington included prompting for appropriate actions when visitor arrive, when somebody goes out and on night time exits. Security reminders prompt if windows or external doors have been left open, and night time occupancy, and bathroom safety modules are in place. Voice prompts were individually recorded with tailored messages to meet the needs of the tenants. These prompts are unique and individual messages can be chosen by the tenants. They provide a consistent and sustainable method of reminder, but can be updated as/if required, a feature that keeps the system dynamic and interesting.

Benefits for tenants and carers

- One of the tenants had previously lived at home with his mother and had been instructed all his life "not to open the door". Since moving into Elmington this tenant has responded well to the voice prompt given when the door bell rings, and as a result of this the tenant has become confident in being able to answer the door and accept visitors to the property.
- Care staff feel that all tenants are more in control of their lives, as the voice prompts only activate if the correct response is not elicited. This enables the care team to step back and provide support/intervention only when and if necessary.
- The tenants' relatives were impressed with the housing and technology solution.
- All the staff feel reassured by the system which provides a level of confidence to them in supporting the tenant group.
- The tenants do not have to wear any devices or controls on their person, as the system detects changes in the environment itself in order to mediate directly with the tenants when required.
- The tenants have embraced the system and affectionately call it "Amy" after the person who recorded the original messages. They have now asked if their own voices can be recorded for the prompts.

Source: Family Housing Association

These types of comprehensive installation with elaborate environmental control system usually involve an amount of fixed equipment, hard-wired into the mains. They are more expensive with capital costs in case study examples ranging from £5,000 - £20,000 per resident.

1.10 Communication aids

The one field in which substantial use of technology is already being made by people with learning disabilities is to aid communications. Applications here include:

- Communication aids that assist or replace speech such as communication boards, Cheaptalk and Lightwriter.
- Information and Communication Technology (ICT); devices to help people with physical limitations use communication devices, like key pads or a mouse; software to aid communication –for example picture and symbol programs and resources like Widgit, Photosymbols, Symbols 2000, Boardmarker, Picture Board.
- Telecommunications such as telephones, mobile phones, pagers and tracking devices.

1.11 Supporting Direct Employment

One new application of Assistive Technology is in helping people arrange and employ their own support and carers.

Home Care Direct

The Home Care Direct base unit is like a dispersed alarm with the capacity to link to sensors. The units prime function is however as part of the system to help people make use of Direct Payments. The unit can record and identify if a carer fails to arrive, the time they spend, check their identity and that they have training appropriate to the tasks required by the individual.

The company, Home Care Direct assists disabled people to take charge of their own care, mostly by using Direct Payments. It does this by:

- Acting as the employer.
- Supporting the recruitment and selection of staff.
- Training staff and providing sufficient supervision with the individual to satisfy CSCI.
- Dealing with all the administration connected with employing carers.
- Utilising the Home Care Direct base unit to remotely monitor the care provided.

Chapter 2   Products, prices and benefits of telecare

This chapter describes the most common telecare products widely available on the market and:

- Explains what each does.
- Gives an indication of cost.
- Suggests the cost benefit trade off of certain examples.

The Steering Group suggested that many service providers and commissioners had not considered AT because they:

- Did not know where to start – where to get products from.
- Did not have sufficient knowledge of what was available and what different devices could do.
- Had little idea of cost and for portable devices often overestimated costs.

This chapter addresses these questions.

2.1 Products – what telecare can you buy off the shelf?

A selection of established manufacturers of telecare equipment were invited to submit details of their current product range along with prices. In a few cases details were already available on websites.

Tunstall	www.tunstallgroup.com
BT	www.bt.com/homemonitoring
Attendo	www.attendo.se
Jontek	www.jontek.com
Tynetec	www.tynetec.co.uk
Vivatec	www.vivatec.co.uk
Initial	www.iess.co.uk
Docobo	www.docobo.co.uk
Nestor	www.primecare.uk.net
Huntleigh Healthcare	www.huntleigh-healthcare.com
Carionetics	www.cardionetics.com
SRS	www.srstechnology.co.uk

A wider list of telecare suppliers can be found on the Telemedicine Information Service website www.tis.bl.uk. Additional websites about AT are listed in Appendix 2.

The tables in this section are an amalgamation of the information provided. They do **not** list every single application but rather are a selection based on the items we found most commonly being used or considered in the course of the investigatory visits.
The price figures quoted are **indicative** only:

- Manufacturer's prices for broadly similar equipment vary.
- The precise specification of products also varies and influences price also whether it is wireless or not.
- Large volume purchases would normally result in a discount.

Tunstall describes itself with some justification as "*a world leading manufacturer and provider of personal and home re-assurance telecare solutions and response centre systems*". It employs 800 people world-wide and is a leading player in Europe having largely established industry standard 'protocols' for equipment (how pieces of equipment link with each other).

There are however a number of other significant but smaller manufacturers, some are listed above. In recent years the ownership or structure of some of these companies has changed. Experience or developments, particularly in Europe, may feed into products purchased in the UK.

Manufacturers will commonly carry out installation for customers. In the case study visits we found frequent examples of manufacturers working closely with local authorities or care providers on 'pilots', 'experiments' or 'trials'. For an individual, family or smaller organisation it is not necessary to deal directly with a manufacturer. Several installations were in effect by a Central Control monitoring service which supplied, installed and programmed the equipment.

Product	Indicative Price (£)	Function – what it does
Dispersed Alarm	180 – 200	The "box" to which a selection of sensors are linked. Automatically dials Central Control (or staff on site/in the area) and has 2 way speech facility – the heart of telecare. Can have recorded messages incorporated and be used to give prompts at a preset time. Are very simple. Individual only needs to understand cancel button.
Intruder Alarm	Varies	A burglar alarm. A good base dispersed alarm unit can use a number of PIR's which can have multiple functions. Dispersed alarms linked to PIR's were in various ways the basis of a number of applications designed to manage risk. Pressing a button can activate PIR's. An alarm can go to Central Control.
Home Safety Package	200 – 300	Some manufacturers supply a "package" of a dispersed alarm, security camera, personal trigger, intruder alarm and a small number of PIR's. More elaborate packages are also marketed.
Bogus Caller Alarm	50	Panic button placed by door. Is possible to have a live intercom link on TV. Can also use broadband to send pictures to someone else.

Product	Indicative Price (£)	Function – what it does
Bed Occupancy sensor	**220**	Pressure is used to detect when a person has gone to bed or got up. By linking with previous life style monitors it is possible for an alarm to be triggered if a person is not in bed by a certain, normal bed time. Can be used to monitor getting out of bed. Getting out of bed detected by this sensor can be linked to turning lights on and off. Or raise an alert if person has not returned to bed after a preset period. Timings can be a problem when people tend not to have a set routine. One organisation reported a failure in a sensor trigger on the alarm when a person fell out of bed.
Chair Occupancy Sensor	**180**	Works in similar way to bed occupancy detector. In case studies used much less than bed sensors.
CO detector	**80 – 90**	Detects excessive levels of carbon monoxide used principally to guard against a blocked flue or a fault in a fire.
Door Entry	**900 / variable**	Can be used to remotely open a door by the individual but the Central Control operator can also use to let emergency services in.
Enuresis Sensor	**50**	Detects urine using a sensor mat. One problem can be false alarms caused by sweating. One provider thought this sensor could benefit about 1 in 3 residents. Provides an immediate alert, means less discomfort for individual, as not left in wet bed and in turn, less laundry and care required.
Epilepsy Alarm	**300**	Detects epileptic seizures by monitoring heart rate, breathing patterns or movement. Alarms can be adjusted and initially may require work over several weeks to match to individuals characteristics. It maybe necessary to trial different manufacturers' products to get one that "fits" the individual's pattern or lifestyle best.

Product	Indicative Price (£)	Function – what it does
Fall Detectors	80 – 100	Worn on a belt they detect falls by using a combination of information such as angle of body, sudden impact/change, and rate of change. One problem can be over sensitivity in the device resulting in false alarms, but in practice most seem to work well and go off appropriately. In some manufacturers products sensitivity can be fine tuned. Quite a short battery life. The maximum reported is about 6 months but some manufacturers appear to last only a month.
Flood Detector	50 – 80	Placed in kitchen or bathroom, senses water. Alarms are small and can easily be picked up and moved about. As noted in the text there are other ways of preventing flooding.
Gas Detector	80 – 120	Detects gas leaks and triggers alarm. Some are very over-sensitive. In practice, in the context of learning disability, this sensor alone would be of limited value and usually it was combined with a shut off valve.
Gas shut off valve	250	Turns off the gas supply if gas leak is detected.
Medication monitor / dispenser	140 – 180	A carousel can be loaded with pills for up to 28 days. The carousel typically looks like a small version of the old 35m slide carousel. The alarm can prompt the taking of medication or sound an alarm if not taken after a certain time and ultimately alerts Control Centre (or staff/carers). One of the issues is who fills the dispenser? Some pharmacists appeared reluctant to provide this service. Relatives are also reluctant to fill dispensers. Some require a 4 hour lapse between taking medication which may not suit everyone's regime. Can bring considerable time saving benefits for District Nurses and others.

Product	Indicative Price (£)	Function – what it does
Mobile Phone	20 – 150	There are small number of simple mobile phones (or phone type) products with built in capabilities including possibly a "panic" button or ability to send information indicating the location of the person. They can be used to summon help, receive guidance and potentially add considerably to individual freedom and competence and security.
Personal Trigger	50	A pendant or wrist button to set off an alarm worn by the person. The issue is wearing, or more often not wearing, the trigger and in some cases danger of wearing an alarm around the neck. For many people the passive alarms are more relevant than personal triggers.
PIR Detectors	30 – 80	Passive Infra Red detectors with many applications. They detect movement or lack of.
Pressure mat	4 – 5	Can detect movement or lack of. So for example getting out of bed or leaving the property can be detected. Can be linked to other functions so for example stepping on a mat turns the room lights on or lights a path to the toilet.
Pillow Alert	350	Provides vibration or turns on a strobe light to warn sleeping person of a danger detected by a sensor, like smoke. Can of course also warn Central Control or on site staff.
Radio pull chord	90	Traditional means of calling for help in sheltered housing was a fixed pull chord. The radio based chords have the advantage they can be placed anywhere. Less relevant to people with a learning disability, but valuable when there are mobility problems.

Product	Indicative Price (£)	Function – what it does
Smoke Detector	**50**	Gives local, audible warning while also sending a signal to Central Control. Most contemporary social housing will already have mains wired smoke detectors. One organisation reported an occasion where one did not send a low battery alert to system. This resulted in the alarm beeping continuously. It took several days for the client to realise that the noise was coming from the smoke detector.
Switches	**Varies**	Come in many guises and can be used to control directly or remotely very wide range of equipment. There are web sites that specialise in switches.
X-10 Controllers	**200 – 300**	These are used in conjunction with other sensors, particularly bed sensors to turn lights on and off.
Extreme Temperature Sensor	**70**	Warns of excessively high or low temperature or very rapid rate of change. They are quite sophisticated and can for example, recognise difference between wet and dry heat. Can alert to a cooker left on or food burning.
Touch Screen	**500**	Can be at heart of communication/ control system. Covered in chapter on communication.
Wanderer Alarm	**250**	Warns when person has left property and/or not returned after a certain time or left door open. Can be linked to pre-recorded message e.g. "John can you check if the front door has been left open". Suggested the message is changed or re-recorded by different person – another resident in a shared house for example – periodically. One instance was reported where a device was installed but the client wanted to leave her door open on warm days. This resulted in repeated false alarms.

The table on the previous pages lists the most commonly used sensors. The process for each individual involves:

- Assessment.
- Purchase of a dispersed alarm.
- Purchase of a selection of sensors from the list.

For a person or a small group of people living in their own home the package would, in addition to the dispersed alarm unit, typically include:

- Some home security sensors e.g. intruder alarm, bogus caller.
- Some environmental sensors according to individuals' requirements e.g. heat, smoke, gas, flood.
- One or two personal devices e.g. a fall detector, epilepsy alarm, mobile phone.

For some people there could in addition be a variety of tailored environmental control items e.g. door/window opener, variable height worktop.

2.3 Tailor-made Assistive Technology

AT purchased 'off the shelf' may only be the starting point for people with a learning disability. People with a learning disability are likely to vary more in the specific type of supports they require than older or physically disabled people because of the broad range of characteristics that come under the label of learning disability. AT and sensors can be tailored to meet very specific needs, for example in relation to eating disorders, diet and behaviour that places the person at risk. AT can be used in some quite imaginative or unexpected ways.

In manufacturing terms some of the products are quite simple, essentially requiring the assembly of components. This means there is a 'cottage industry' element. Manufacturers may be able to produce bespoke equipment. Some of the products offered by suppliers are made by another company and "re-packaged". It is also possible to get compatible products from other European suppliers. For example: in the course of our visits we came across a care provider testing a new, very thin, enuresis pad which came from Finland.

This means if the equipment available 'off the shelf' does not quite meet the needs it may still be possible to get equipment made or to modify existing products. Some of the bigger manufacturers have also been willing to do this; but feedback from case study visits suggests that the smaller market for learning disability applications, combined with an approach whereby services are tailored to individuals, may not always be attractive for providers of equipment.

There has been an example in the USA of a provider working with an engineering department in a university to develop a mechanism that enabled a person to be turned over in bed every hour in the night without the help of support staff. This was attractive to the university because it gave the students a challenging project with good learning outcomes, and gave the individual a highly specialised piece of equipment that would not be viable for a manufacturer to produce.

As the first example below illustrates, tailor-made AT does not need to be complicated, expensive or require specialist knowledge. The second case study in this section illustrates the imaginative application of a modern, personal monitoring device, worn on the wrist, to dramatically improve the life of an individual.

Case Study

A family's own initiative to install one single device

"**The problem** is that my son has a compulsion to play with water. This can be disruptive and create a mess".

Capability requirement: to separate the water and son without causing their son to display difficult to manage behaviour

This needs to be:
- Practical – easy to use.
- Secretive – he learns by watching.
- Effective – the water must be shut off totally.
- Efficient – the system should be as simple as possible.
- Safe – no high voltages involved.

Answer
Using a normally open valve, to ensure effectiveness and efficiency, a low voltage operating system to ensure safety, and a remote control to ensure secrecy. We have put together a system which is:
- Simple to install.
- Cheap.
- Uses off-the-shelf technology which is CE approved.

How does it work?
The valve is fitted in the water pipe/s. When inactive, water flows through it. The power to supply low voltage current for the valve is supplied by a transformer similar to that used for charging mobile phones. The transformer is plugged into a standard 433 Mhz transceiver, which in turn is plugged into a wall socket. The transceiver is sent a signal from a key ring transmitter. The transceiver receives the signal, and switches power from the wall socket through to the transformer. The transformer supplies low voltage current to the valve/s. The valve/s operate, switching off the water.

What effect did this have?
Son operated the tap, but on seeing no source of water immediately lost interest and left the vicinity of the sink quietly. We believe that because he saw no connection between the parent (operating the remote) and the tap, there was no possible complaint he could have with the parent.

Any other issues?
Yes – always remember to check the taps are off before switching the water back on! Never let him see you using the remote! Cost – about £70 for the parts. Work – a bit of straightforward, simple plumbing.

Source: Father/Bromley Autistic Society

The next example is a more elaborate installation based on a personal device with dramatic results for the individual and carers.

Case Study

Vivatec, a provider of AT, adapts an existing device to meet the needs of Oliver, a young man with Prader Willi Syndrome (PWS)

Vivatec specialises in advanced personal and environmental monitoring systems. One of their main products, WristCare, is an advanced social alarm that is worn on the wrist and can be used to call for help much like a pendant. Its more sophisticated use is to detect wandering and medical emergencies. It also monitors activity and routines such as sleep, bathing, going out etc.

Vivatec was approached by an OT supporting Oliver, a young man with Prader Willi Syndrome and learning disabilities. This syndrome results in an obsession with food.

A solution was needed that stopped Oliver from stealing food from the kitchen without restricting anyone else in his household.

Vivatec was able to adapt the WristCare system to alert his mother through a pager system whenever he entered the kitchen. This worked through placing a sensor in the kitchen that detects when Oliver enters the kitchen wearing the WristCare. It will also alert his mother if he takes the WristCare off.

This has resulted in Oliver ceasing to try and get to food in the kitchen and has also helped him to relax; because the device is 'foolproof' he does not obsess about trying. His mother and two sisters can carry out normal life at home without having to be constantly vigilant. Oliver himself is very pleased with the way the system works.

The setup was costly because it was geared specifically to Oliver's needs and Vivatec had to fund the majority of the costs in order to test the use of WristCare. The total cost was approximately £12,000 with Vivatec funding £9,000 and the local authority funding £3,000.

Part of the WristCare system is activity monitoring and this has shown that Oliver has very little stage 3 and 4 sleep which is the deep and restful stage of sleep where energy is regained and hormones are released for growth and development. A lack of growth and development is a feature of PWS and may have some connection with a lack of sleep. This shows an exciting potential to use WristCare to understand more about PWS and other conditions, particularly where people with learning disabilities are unable to describe symptoms they are experiencing.

2.4 Central Control and response services

When an event calls for action by a carer the alarm equipment can route calls in a variety of ways:

- To staff on site or nearby.
- To a specified person.
- To Central Control who in turn take decisions on how to route calls, including calling out emergency services.

When an alarm is triggered systems typically go through a sequence, calling people in a pre-determined order according to time of day or other instructions.

In any modern service supporting people living independently in their own homes (or with parents) a Central Control service is likely to be key even if it is the last point to which calls are routed. The possible exception is when there are a number of staff always on site, 24 hours a day.

Monitoring services have been set up by:

- Many local authorities – initially to support sheltered housing.
- Some housing associations who support a significant number of older people in sheltered housing or at home.
- Private companies.
- A small number of charitable agencies who specialise in the welfare of older people, such as Help the Aged.

Control Centres are numerous; it is a competitive market and a basic monitoring service can consequently be purchased for less than a pound per property, per week. Many commentators expect some rationalisation of the market.

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Example cost of monitoring

Equipment can be leased. Sample weekly charges are:

Basic dispersed alarm	£1.10 per week including VAT and maintenance
Sensors	£0.30 - 0.75 per week depending on device
Monitoring by Central Control	£0.60 per week

Source: Astraline

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We found that other examples of packages of a dispersed alarm and five or six sensors, plus a monitoring and maintenance service, ranged between £5 - £8 per week.
Two further points on monitoring costs:

- The resident needs a telephone point and a power socket nearby. If there is no telephone this is an additional cost.
- The way the social alarm market works is that private individuals, in their own homes tend to have to pay much higher monitoring charge – perhaps £2 - £3 per week. The prices quoted in the box above are based on a contract with a care provider.

In principle, Control Centres can be located anywhere; so while many local authorities have decided they must have their own service this may not have been technically necessary. However, for people with learning disabilities it may be extremely important, even essential, to be able to give a direct, personal response, quickly. This might come from a care provider, contracted to deliver a wider package of care to the resident. In this case the response to an alarm will be for Central Control to follow an agreed protocol routing calls to the care provider's staff. It could be that all calls go directly to on-site/nearby staff or to staff directly in pre-determined time periods.

Alternatively and increasingly Central Monitoring services are establishing a 24 mobile response service in various guises. If the care package includes use of the Central Control response service then it may be more relevant and important that Central Control has a reasonably local base.

Telecare Services Association

Most major providers of a social alarm monitoring service are members of the TSA and can be found listed on the website. The TSA has produced a set of standards and code of practice for the management of social alarms. This has three elements:

- Call handling.
- Dispersed alarm operation.
- Response service.

There is a specification for community alarm systems based on central control monitoring. www.asap-uk.org
Tel: 01634 304200

2.5 People with learning disabilities using Assistive Technology

It is difficult to find many examples of people with a learning disability using AT. The only area where there has been significant growth is in using AT to support communication for people with a learning disability. There seems to be a similar pattern of use in Australia and the United States, where there has been very little use of AT to support people with a learning disability to live independently but there seems to be greater use of AT for communication than in the UK. The following is an example of an American support organisation that is experimenting with supporting people with a learning disability to use AT.

Case Study

An example of the use of Assistive Technology by people with a learning disability in the USA

Hope House Foundation provides supported living to people with a learning disability in Virginia, USA. Hope House has an international reputation for providing ground breaking and creative person centred supports for people with a learning disability. Robin Haverty, Services Director at Hope House, gives a perspective on the use of AT in the USA and how Hope House has sought to expand its use:

"I do not know of any provider who is consciously using AT as a component of service design and we (Hope House) are very much in our infancy in terms of incorporating technology into services and the lives of people we support, but we are working on it, and I will describe our progress thus far.

"In the States, AT is widely written of in both laws and regulations as being available to people with developmental disability, but rarely used it seems for this population. Case managers, who are the first approving body for service/funding requests, know little if anything about the different funding streams that are available for environmental modifications, AT, and professional consults (OTs, rehab engineers etc). This has been the first barrier, since case managers neither promote AT as a 'wrap-around service', nor in many cases have any idea how to access the funds when they are requested. In some cases they have even denied (out of ignorance) the very services they are charged with accessing, that the funds for such items exist.

"In Virginia, environmental modification is defined as changes to the home or work structure – things that if you packed up and moved would remain. AT items are considered to be those things that would go with you.

"AT as defined here in Virginia is much more exciting, but the barriers are multi-layered. Certainly the first barrier is unwinding the secret to achieving funding approval, as this is a funding stream almost entirely untapped by this population, but it is also working in an environment where people with developmental disability have always been identified, funded and staffed based on level of disability.

"The answer for any skill deficit has been staff assistance. Any decrease in ability has typically been responded to with an increase in staffing level. AT begs you to see things differently. Lastly, in general we tend to think of AT as limited to high tech or computer type items, when in actuality everything we use, a can opener, a dishwasher, vacuum cleaner, and Velcro are all examples of AT. Changing these perceptions and helping staff begin to see things differently has required as much if not more attention than the funding."

continued overleaf

"Hope House has supported a committee to work on this. We have been working purposefully on this since January 2005. We have some small successes:

- Several people have gotten lift chairs so that they are able to rise from a comfortable seat without staff assistance.
- One man has gotten a trapeze bar for his bed so that he can get up without staff helping him up in the morning (this has totally and quite unexpectedly improved his morning mood, clearly demonstrating that you never know how just one little thing might impact someone's happiness).
- Several people are using picture phones and are now able to successfully contact family or staff by phone where previously they were unable.
- Several people are using medication boxes that provide a verbal prompt when it is time to take the meds inside.
- Several people use watches that verbally tell the time when a button is pushed.
- Several people use stretch shoelaces if they have been unable to tie shoes but want to look 'hip' and don't care for Velcro.

"These examples really represent 'practice' on our part, both in securing funding and in starting to change how we see and address areas where we, as staff, provide assistance or training. All the above examples were areas where heavy staff involvement, primarily in the nature of physical assistance, was provided. Our incorporation of AT is also with the idea in mind that we, as staff, could be involved with people in more meaningful pursuits rather than spending the bulk of our time in training or assisting in the more mundane activities of daily routine.

"Our committee has developed connections with professionals (such as OTs, physical therapists, physicians, and suppliers) to endorse the requests we make for funding, since the opinion of staff alone is not enough to attract funders. Our next step as a committee has been to identify several individuals in our agency, and along with the teams of staff that serve them, really look intensely at their daily routine, and look at the areas where staff are involved, with the goal of increasing independence in those areas. Along with that we intend to look at less concretely clear areas of personal preferences and leisure to examine how AT might play a part in improving quality of life in those areas as well.

"We have just begun with the first individual, and have identified two others as our 'guinea pigs' for learning. We chose people that are very different in cognitive function, physical ability, age, interests, etc; people that we thought would give us an opportunity to learn and explore and would not be adverse to our attention."

2.6 Telecare for people with a learning disability

In doing this report, we came across several isolated, 'one-off' examples of where telecare has been used to support people with a learning disability to live more independently. There are fewer examples where providers or a local authority are using it as a mainstream response for people with learning disabilities.

One concern in expanding the use of telecare to people with learning disabilities is the competence of Control Centres to handle calls well. One very large RSL in this study explained that although they had a specialist team of five people dealing with calls from residents of sheltered housing and extra care within their general Call Centre (which takes

Examples of Telecare being used in one learning disability service

- Helpline phones.
- Cameras monitoring entering and exiting from someone's house.
- Helpline pendants.
- Pressure mats linked to alert people when people get out of bed often linked to house alarm.
- Front doors linked up to an alarm and pager service.
- Sensors around someone's bed to alert when they have a seizure, as long as arm raises and breaks beam.
- Baby monitor next to person's bed with base unit in sleep-in room.
- Bleeper on front door to alert on site staff that someone is leaving or entering building.

In addition currently being trialled are:

- 'Sensor care' equipment which alerts on site staff if person gets out of chair or bed. The aim of this is to offer more timely assistance and avoid falls.
- 'EMFIT' seizure monitoring sheet which goes under the mattress and can detect and monitor heart rate, breathing and detect seizures. This is to replace an array of sensors in use by someone who has infrequent but life-threatening epileptic seizures.

all types of phone calls for residents), they would not be confident in their ability to handle calls appropriately from a different needs group. Similarly, mobile wardens would be unlikely to have specialist training or knowledge. They felt:

- A specialist care provider should generally be the responder.
- There was a case for a national Call Centre dedicated to dealing with calls from people with learning disabilities.

Anybody who becomes interested in telecare will soon come across the West Lothian Council. There are dozens of SMART home demonstrations around the country and numerous pilots. What is different is the strategic approach of this Council, which is one of the few authorities where telecare is now mainstream provision, albeit mostly for older people.

West Lothian Council Home Safety Service

Astutely marketed as 'home safety', comprehensive telecare equipment has been installed in 1700 properties with residents aged over 60. The target is to install the package in all 10,000 homes in the area occupied by older people.

The cost of the service is £4.87 per week. This includes the telecare equipment, monitoring and a mobile response service.

The telecare package includes a dispersed alarm unit and a range of sensors to detect activity/inactivity, intruders, falls, smoke, flooding, and extremes of temperature.

Another local authority which has supplied fall detectors and social alarms to people with learning disabilities for some years reported that their own Control Centre had coped well following initial training. Similarly, a housing association which runs Astraline has a number of people with learning disabilities already connected.

It is the ability to provide a prompt, personal response to calls, 24 hours a day that was thought to be fundamental to the development of telecare in this field.

Kent County Council – telecare project

Kent County Council committed a fund of £2.25m to provide telecare to people who met a broad eligibility criteria, which included people with a learning disability. From April 2005 people must be eligible under Fair Access to Care. They are currently piloting this project in three of Kent's twelve districts. They are supporting approximately 300 people with telecare, 30 of whom have a learning disability.

They have appointed one project manager and three project officers who have a good knowledge of telecare. Kent is aiming for telecare to become a mainstream service response in the long term, so they are concentrating in areas such as raising awareness with care managers, OTs and housing officers, and working with resource allocation panels to ensure that it is being considered in all cases.

At present, service users have a specialist assessment with the telecare provider, involving the care manager and OT with the intention of training these professionals in assessment. So far, the use of telecare by people with a learning disability has been successful. The main devices that people with a learning disability are using are:
- Pendants to contact a call centre.
- Smoke alarm.
- Key safe – a system where an outsider can gain access to the property in an emergency.
- A movement sensor that is used like a burglar alarm to protect the property.

A practical example has been a person who recently moved into their own home who was unsure what to do when they had a headache and earache; using telecare they were able to talk through what to do with a person at the call centre.

Some people with a learning disability have telecare as their only form of support as a safety net and have not actually used it yet, whereas some people use it as part of a wider support package to enhance the quality of support. Some of the main benefits for people with a learning disability who use telecare have been:
- Peace of mind for the person, their carers and family.
- The person does not have to do anything to make it work.
- If a person is at risk, it is a way of supporting them 24 hours a day.
- It has allowed family carers to leave the person at home to get out and do some shopping for example.

Kent is keen that telecare is not used as a way to cut services or reduce staff hours; instead it should be seen as part of a range of support options and an enhancement to the quality of support. It is planning to extend the pilot to a further four districts and to have a focus on telecare for people with learning disabilities in two of the districts in order to understand its use in this area.

2.7 Benefits

In this section we outline gains from AT found in the case study applications.

Service quality for resident:

- Privacy.
- Dignity.
- Control of environment.
- Enable to do more for self.
- Enable to do more independently.
- More reliable in delivering safety.
- Quicker or timelier response when needed.
- More timely response can result in greater comfort and/or less harm to self.
- Fewer disturbances – in particular sleep at night.

For staff:

- Safer working environment.
- Less routine monitoring required.
- Greater satisfaction when enablement occurs.
- Extends skills, create wider range of jobs.
- In some organisations can create a better career structure.

Financial:

The principal financial benefit flows from needing fewer staff doing very limited tasks. The cost savings lie in these areas:

- Eliminating need for permanent staff, in particular sleep-in staff "just in case".
- Replacing working night staff by sleep in.
- Reducing overall number of staff.
- Allowing residents to do more tasks themselves or unaccompanied.

There are some caveats on the proposition that telecare or other AT will automatically achieve savings or that savings will equate to the difference between a staff salary (plus overheads) and the depreciated cost of equipment plus monitoring and maintenance:

- AT will not always deliver direct savings. It may simply deliver a better, safer, more reliable service. Environmental Control equipment may simply be enabling.
- Introducing telecare may mean changing the way some support is provided i.e. some sleep in staff become mobile staff covering a group of residents. This may in turn mean higher travel costs or a higher salary.
- Ongoing training is required around AT and also to keep abreast of new applications that might be of benefit.

The key point here for people with learning disabilities is that **telecare can be used to deal with risk**. In the process it may also give someone greater privacy, freedom, and a more reliable, safer service. This will become apparent as we look at other examples. AT more generally can do more than manage risk.

Risk Management - sleep in and shared house

Two friends moved together from residential care into a house they now share. It became apparent that although there was sleep in cover costing £33 per night this was never in fact called. A dispersed alarm (Lifeline 2000) and a normal array of passive sensors such as flood, smoke, heat was installed.

The alarm is linked to a control centre run by a housing association. In the event of an alert Central Control routes calls to a mobile phone carried by staff from the residents' care provider. The staff who have agreed to be called are those who provide normal support during the day and can be at the property within 10-15 minutes. A small amendment to the employment contract has been made. As a back up the housing association also employs mobile staff and if necessary Central Control would call out police, ambulance or fire services (according to the nature of the alert).

The capital cost is £650 and weekly monitoring charge is £8. All the costs are met by Social Services. The capital cost will be covered in the first month.

Gains to the residents include more autonomy, and not having to share their house with anyone at night. The sleep in cover has been reduced gradually to reassure parents and staff of the reliability of the system.

Source: Cumbria SS

2.8 Costs and benefits in practice

In this section we outline the actual process one care provider introducing telecare and other AT for 33 people living in 10 properties went through, and the financial results. (Example provided by West Glamorgan Housing Consortium).

The service is based on group homes with two-five residents in each. There is a wide range of abilities. Many have physical disabilities, epilepsy or difficulty in communicating. A number of them are incontinent. Most of the services provide 24-hour care.

An experienced development manager, who has become the organisation's expert in AT visited each property and met residents. He then discussed with staff how they were currently supported, particularly at night, identifying the critical support issues for each person.

An abbreviated example of the results for one property accommodating three people illustrates the approach.

Overview of Service's night-time support

The service employs wakeful and sleep in staff cover. The wakeful is employed to monitor epilepsy, possible choking and provide reassurance to one user who can experience psychosis. The wakeful also carry out 'rounds' every 15 minutes on each of the service users. The sleep in has historically been provided for a previous service user. Currently there is very little intervention required by the sleep in. The sleep in is used to support the wakeful in the occasional personal care or manual handling should one resident fall out of bed.

Service user specific: A

Support need	Service response	AT support
XX has had a recent fall and has become very unsteady on his feet. XX is prone to falling out of bed.	Regular checks by staff. Staff have used chimes on the edge of the bed to alert them when XX may be getting or falling out of bed, however XX is getting out of the other side.	A bed sensor (or epilepsy sensor) would alert staff when XX is out of bed. The bed sensor (not epilepsy sensor) could also turn on a bedside light if additional reassurance for XX was required. There doesn't appear to be anything we can do to stop XX getting out of bed. It may be worth considering a high/low bed which could reduce the risk should XX fall whilst getting out of bed.
XX can also experience "mini strokes" where his skin turns "grey".	Regular checks made, staff are concerned that they miss these.	An epilepsy sensor can also detect hyperventilation type activity; it is unclear whether this would be an adequate solution for this need. I would need further information regarding the physical symptoms.
XX also has incontinence needs.	Staff identify when XX needs changing as part of their checks.	An enuresis monitor could be provided under the mattress to alert staff when XX actually needs support in this area, rather than staff checking for the just in case.
Asthma attacks	Regular checks	Epilepsy monitor, utilising the ability to detect changes in breathing activity and possibly convulsive type behaviour which can be present during asthma.

Service user specific: B		
Support need	**Service response**	**AT support**
If out of bed will chew various items around the home.	Staff may need to intervene when XX gets out of bed.	Bed sensor to alert staff to XX getting up.

Service user specific: C		
Epilepsy –
Risk of choking/ asphyxiation by chewing on bed clothes or bedding. XX is also in the later stages of dementia and she is also blind.	Regular checks made by wakeful staff.	Epilepsy monitor to alert to epileptic fits it also has the capacity to pick up on changes to breathing such as hyperventilation or asphyxiation caused by choking. If required the epilepsy monitor also has a built in absence alarm to alert staff should XX fall out of bed.
The purpose of the monitor would be to support staff rather than make changes to the staff cover. Staff are especially concerned about the risk of choking and whether they may miss this happening.

Summary

The staff seem most concerned about the following areas:

■ A and the risk of injuring himself whilst getting out of bed.
■ C choking.

The assistive technology solutions available would serve to reassure the staff and provide a more reliable way of monitoring and alerting staff to risk. A bed monitor for A could ensure A's additional safety.

The sleep in is difficult to justify. It was provided for a previous service user. The 3 month assessment results identified that the sleep in was only required twice. Given that it is required so infrequently it would be adequate to have access to a night time response for the occasions that require a secondary staff member. Both the staff and service co-ordinator accept this view.

The most common applications that would improve the situation for individuals were:

■ Epilepsy alarms.
■ Enuresis alarms.
■ Pressure pads.

The review of 33 people resulted in the purchase of the following equipment at a gross cost of £10,341.

AT	Quantity	Unit cost	Total cost £
Epilepsy monitor	6	279.00	1674.00
Enurisis (incontinence) monitor	13	125.00	1625.00
Bed sensor	5	193.60	968.00
Chair occupancy sensor	1	155.76	155.76
X10 Light system	2	93.80	187.60
Additional "Amys" (alarm triggers)	4	39.50	158.00
Pagers	4	369.00	1476.00
2 year licence for pager (per site)	1	60.00	60.00
Vibrating pillow pad (inc. strobe light)	1	315.00	315.00
Door contacts	4	73.00	292.00
Lifeline 4000++ (dispersed alarm base unit)	10	149.00	1490.00
Training for the above	1 day	400.00	400.00
Total			**8801.36 + Vat (£10,341)**
The above do not include on-costs such as ongoing maintenance and battery replacement. There is also a need to replace some of the sensors each 12-24 months.			

The introduction of AT enabled the care provider to:

■ Replace 7 sleep in staff.
■ Change waking to sleeping night cover.

This achieved a direct salary cost saving of £122,000. This is only part of the story. The introduction of AT and this service review also changed how some services are delivered. In order to replace permanent sleep-in staff, who may in practice do very little most of the time, a mobile night response service of two people was created. This cost £54,000 per annum. Thus the net saving is £68,000.

This (waking) mobile response service:

■ Comes to properties at critical pre-determined times.
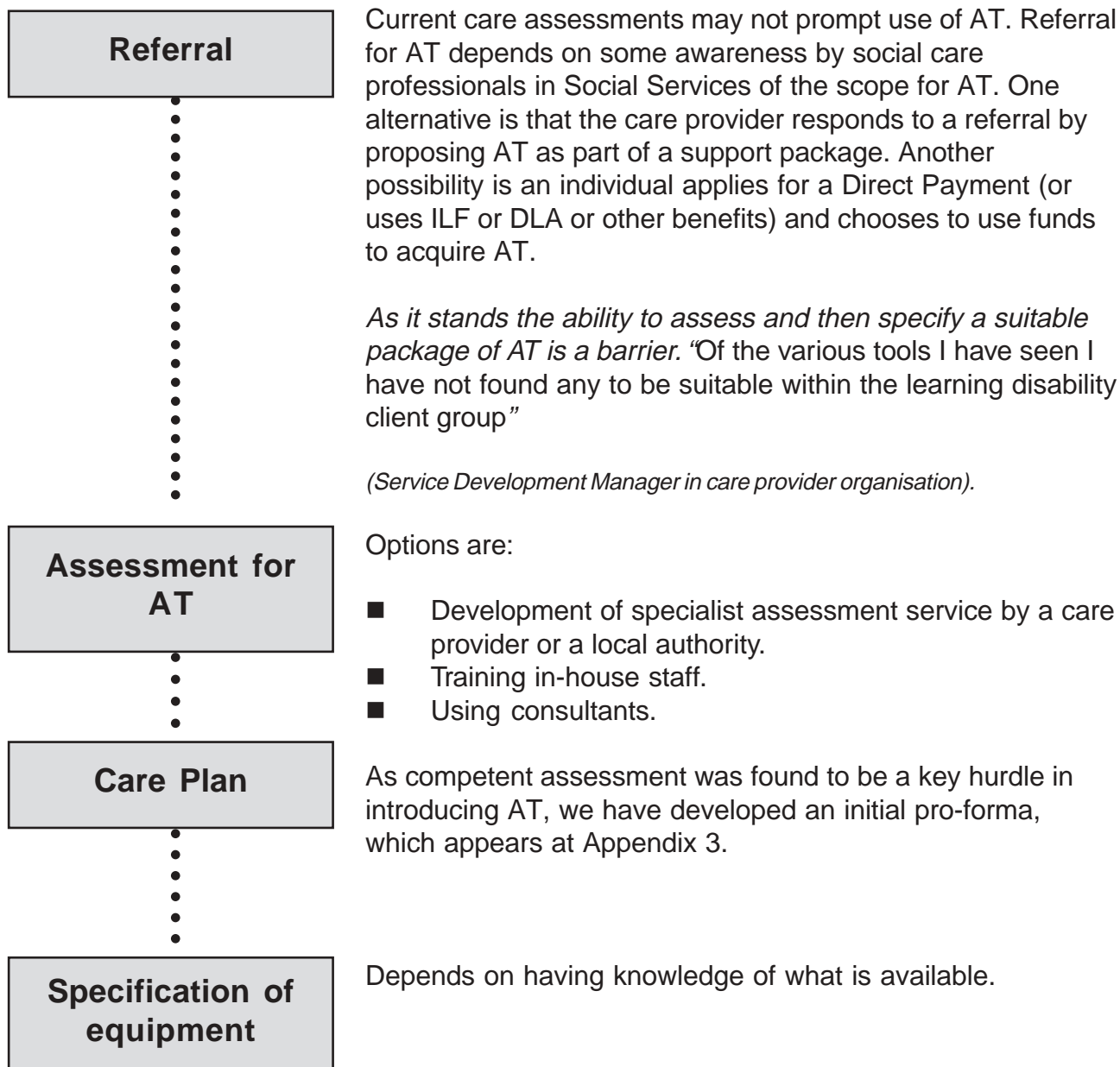■ Answers alerts/alarms.

Chapter 3   Assessing, specifying and installing telecare

3.1 Process

There is no standard procedure for assessing and providing telecare. The process is likely to vary depending on who initiates it (either the housing provider or the individual). With the advent of individualised budgets, there is likely to be more initiation from individuals who will choose AT as part of their support package. Depending on the sophistication of the device, there is still likely to be some input necessary from professionals in assessing, specifying and installing telecare, however there is no reason that a person holding their own budget could not purchase directly from the manufacturer or supplier.

From a care manager or provider's perspective the process of going from a new person being identified for a service to having a tailored telecare package in place looks like this:

Issues

Referral

Current care assessments may not prompt use of AT. Referral for AT depends on some awareness by social care professionals in Social Services of the scope for AT. One alternative is that the care provider responds to a referral by proposing AT as part of a support package. Another possibility is an individual applies for a Direct Payment (or uses ILF or DLA or other benefits) and chooses to use funds to acquire AT.

As it stands the ability to assess and then specify a suitable package of AT is a barrier. "Of the various tools I have seen I have not found any to be suitable within the learning disability client group*"

(Service Development Manager in care provider organisation).

Assessment for AT

Options are:

■   Development of specialist assessment service by a care provider or a local authority.
■   Training in-house staff.
■   Using consultants.

Care Plan

As competent assessment was found to be a key hurdle in introducing AT, we have developed an initial pro-forma, which appears at Appendix 3.

Specification of equipment

Depends on having knowledge of what is available.

| **Installation** |

This too is a problematic area at present with varying approaches and experiences illustrated in case studies. Broadly the options are:

- Installation by manufacturers – satisfactory for standard products.
- Employing consultants who work with the housing or care provider.
- Using one or more electrical contractors.
- Learning to do it yourself – there are several examples of this.
- Using a Central Control provider.

| **Alarm receiving** |

The principal options are calls:

- Routed through central control.
- Routed direct to local/on-site staff via pager or mobile phone.
- Routed to another specified responder such as parent.

| **Response** |

A call centre will follow an agreed sequence in dealing with calls depending on the nature of the alert. For some people with learning disabilities a rapid direct staff response will be vital. As ever the best answer will depend on the individual and the circumstances.

The case study visits underlined:

- The need for continuous training of care staff in AT so they understand what is installed but also what may be possible and can develop and adjust support as well as some of the devices.
- Training service users in the technology as far as possible.

Getting competent help and advice, seeing and testing equipment is one of the barriers to greater use of AT. How can someone with a learning disability select for themselves a package of technology? In addition to consulting manufacturers and monitoring service providers, possibilities include:

- Visiting a SMART home demonstration – there are quite a few around the country.
- Visits to some of the organisations mentioned within this study.
- Advice from OTs.
- Community Equipment Stores – discussed in Chapter 5.
- Disabled Living Centres.

Disabled Living Centres

Disabled Living Centres have centres in strategic locations in England, Scotland, Wales and Northern Ireland.

They provide information and advice either from their Centres or over the telephone. The Centres do not sell AT products and therefore give unbiased advice on what items would be useful to an individual, how they work, cost and availability. If you are able to visit a Centre you can try out products for yourself.

Disabled Living Centres:
■ Offer solutions to practical difficulties in daily living.
■ Are specialists in Easier Living Products designed to help a range of activities, from opening a jar to getting into the bath.
■ Offer opportunities to see and try out a wide range of products.
■ Provide unbiased expert advice and information about what is available, how much it costs, and where to get it.
■ Are for disabled people, their carers and people who work with or for them on a professional basis.
■ Are also used by a wide range of professions and trades as a source of information about access, design and other issues related to daily living.

The Disabled Living Centres Council website can be found at http://lut.ac.uk/info/usabilitynet/dlcc.html.

"I used to think that being disabled meant that a lot of everyday activities were impossible, or at best, extremely difficult. All that changed when the DLC was set up. Now it's wonderful to know that I can find practical solutions and alternative ways to achieve what I want to do. Even though physically I can do less now than I could do in the past, I can actually be more independent, because I've got the right equipment."

Source:www.dlcbristol.org/default.asp

Centres for Independent Living

National Centre for Independent Living – www.ncil.org.uk is a not for profit company run by disabled people. It gives advice on independent living, Direct Payments and support to Personal Assistant Users and Personal Assistants. There are local Centres for Independent Living (CIL) around the country. Certain centres have a payroll service which people in receipt of Direct Payments are able to use to pay Personal Assistants, thereby relieving the person with learning disabilities of the worry of tax, NI and the administration associated with employees.

Most Local Authorities have a person that will be able to advise or to direct people to the nearest CIL.

It has been suggested that Centres for Independent Living could become sources of independent information but at present their involvement in this area seems limited.

3.2 Lifestyle Monitoring

MIDAS II stands for Modular Intelligent Domiciliary Alarm System. Developed originally by Dr Kevin Doughty at Technology Healthcare systems for monitoring how people live and use their property and equipment, it is now commercially available. It consists of two elements:

- A wide array of sensors installed in the property monitoring when you get up (bed occupancy), use of toilet, use of cooker and kettle, when you wash/bath, temperature, noise levels (playing TV/video/music) and similar information.
- Computer software that analyses lifestyle, producing graphical displays and other information.

This kind of installation can be valuable in two ways:

- As a unique and unobtrusive part of the assessment to understand what kind of support – including AT – would be most valuable. For example, monitoring shows repeated visits to the toilet at night. This might suggest that a pressure mat by the bed is used to turn on lights illuminating the path to the toilet and back to bed.
- Having established a normal pattern of behaviour, significant deviations can be detected and staff alerted to the need to at least investigate. Using the same example: a resident who normally sleeps through the night might suddenly start going to the toilet six times during the night. This might suggest a urinary infection.

Lifestyle monitoring offers also a 'virtual visit'. Staff can monitor wellbeing constantly, remotely (and arguably more reliably) without the need for a member of staff actually entering a resident's property (with all the invasion of privacy, risk and expense implied). So the computer screen at the Call Centre or 'care provider' office might show:

Bedroom	**Bathroom**
Bed - occupied Room - no movement Last movement - 10.30 Electrical equipment - off Lights - off	Bath - empty Room - no movement Last movement - 10.15 Water - off Lights - off
	TIME: 10.50

3.3 Telecare assessment

Inadequate knowledge and experience in assessing people with a learning disability in relation to AT was seen as a significant barrier. A few organisations thought they could develop a specialist service to carry out assessments. Most were relying heavily either on a small pool of independent consultants/academics or manufacturers of equipment, often in conjunction with an OT or a member of staff with a particular interest in AT.

As noted elsewhere a small number of trials of MIDAS II are taking place where an array of sensors are used to monitor and establish a person's life style and abilities to in turn help determine the best package of AT (and support).

There are few paper based systems designed for assessment of someone with a learning disability for telecare. Set out at Appendix 3 is an outline of a basic form which organisations can adapt and develop to suit their requirements. The skeleton prepared for this report is based on a number of pro-formas used by different organisations, mostly in screening older people for possible telecare packages. In practical use the pro-forma would probably require additional information and tailoring to the organisation and circumstances in which it is being used.

3.4 An Assessment house

We found several local authorities had, or were in the process of setting up, a building in which assessment of an individual could take place to develop a tailored package of support, probably including AT. Typically, occupation was limited to no more than six months. A key feature of this new breed of 'assessment home' is the introduction of technology as part of the assessment process.
It was argued the unobtrusive technology could:

- Create a more accurate assessment of what an individual actually could do.
- Avoid excessive and possibly unnecessary intervention of staff/carer, distorting assessments.
- Demonstrate what role technology might play as part of a long term support package, showing what was useful or what was unnecessary.
- In the process provide a reliable means of managing and limiting risk.

The 'Assessment House' is an example of where a computer sits in the middle and is able to initiate action according to set instruction or scenarios. In this case the following 'software' modules are planned:

- **Visitors.** This module is to remind the occupants that, if the doorbell rings and they go to open the door they should use the video door entry system and not let strangers into the house. The system should notify the carer that the doorbell is being answered:
    - ☐ door bell rings.
    - ☐ movement detected in hallway.
    - ☐ loudspeaker message and local carer alerted.

- **Going out.** This module is to remind occupants to take their keys when they leave and to let the carer know they are leaving. The system should notify the carer that someone may be leaving the dwelling:
    - ☐ movement in hall.
    - ☐ external door opens.
    - ☐ loudspeaker message and local carer alerted.

- **Night exits.** This module is to alert the carer if an external door is opened during the night.
  - ☐ *night exits* – if external door opens local carer alerted.

- **External door open.** This module is to alert the carer if an external door has been left open too long.
  - ☐ *at any time* – if exterior door open for stated time alert carer.

- **Open windows.** This module tries to prevent open windows on the ground floor, which may pose a security threat if there is no-one downstairs. During the day it attempts to get the residents to correct the situation and if this fails it alerts the carer. At night it alerts the carer immediately. There is an option during the day to switch the module off until night time.

  ### Module 5.1   Daytime
  - ☐ occupancy of ground floor becomes zero.
  - ☐ a ground floor window is open.
  - ☐ loudspeaker message (message to be defined) if not rectified in stated time then alert carer.
  - ☐ if carer indicates to system situation OK module cancelled until night time period begins.

  ### Module 5.2   Night-time
  - ☐ ground floor window open.
  - ☐ local carer alerted.

- **Night-time occupancy.** This module is to check that the correct number of people is in the house at a pre-set time of night. The carer has the option of cancelling the warning if they know there is not the usual number of people resident.
  - ☐ Monitor occupancy from start of night-time.
  - ☐ Alert carer if occupancy is above/below a stated value at a stated time.
  - ☐ If carer indicates to system situation OK module cancelled until next night-time period begins.

- **Bathroom safety.** This module is to provide means of someone asking for help while in the bathroom without having to leave room.
  - ☐ help buttons in bathroom.
  - ☐ when button pressed carer notified.

- **Local carer contact.** This is to assist carer(s) in managing risk by notification of potentially hazardous situation and handing over management of the situation to the carers at a defined time.
  - ☐ cordless telephone connected to each system.
  - ☐ all calls must escalate to call centre when local carer has not answered appropriately.

- **Diagnostic.** Functionality required to ensure correct operation of the Insight.
  - ☐ all system activity including sensor activations, system and sensor faults and mediations should print to a log file.
  - ☐ system and sensor faults should cause the system to transmit a log file immediately for system support and maintenance.
  - ☐ main power failure should be notified to the carer and cause a log file transmission.

Chapter 4   Communications and Assistive Technology

AT to aid communication is well established and has widespread use, particularly for people who have a physical or sensory impairment that affects verbal communication.

It is less well used with people who have a learning disability; but in recent years there has been a more widespread effort to enable people with a learning disability to communicate and understand communication more easily. The three main areas of AT for communication are:

- **Communication aids** that replace or augment speech, such as a Cheaptalk communication board, Lightwriter or Typetalk.
- **Information and Communication Technology (ICT):** hardware and software to use with an ordinary computer such as overlay keyboards, touch screens, a special mouse; software programmes to aid communication using symbols and photos such as Widgit, Boardmaker and Photosymbols, as well as internet, email, word processing and presentation software.
- **Telecommunication:** Telephones**,** mobile phones and pagers that are designed to enable people with a learning disability to use them more easily.

This chapter focuses on communications and AT that can support people with a learning disability to live more independently.

4.1 Communication aids

A communication aid is anything that helps an individual to communicate more effectively with other people. This can range from a simple letter board to a sophisticated piece of electronic equipment that enables the person to type and has synthesized voice output.

It is not essential for the user to be able to read text in order to use a communication aid. Many aids are symbol based and still provide full functionality in order to communicate with others.

An electronic communication aid can be a device that has been purposely built for that job, and nothing else, or a standard computer running specialist communication aid software with the added benefit of being a computer as well.

A communication aid alone may not necessarily help a person with a learning disability live more independently than if they did not have it. For many people with a learning disability that need a communication aid, it is more likely that they will have a level of need that requires them to have support staff with or without the aid. A communication aid however can enhance communication of choice that may be difficult without an aid and this is likely to improve the individual's quality of life. More information about communication aids can be found at the Communication Aid Project – www.cap.becta.org.uk.

Lightwriter

SAM Communicator

Simple communication device

Case Study

Cinnamon lives in her own home and has a team of support staff who support her 24 hours a day. Cinnamon does not have verbal communication but is able to answer closed questions by blinking twice for no and once for yes. Cinnamon also uses a voice output communicator and this has a range of symbols and pictures that relate to everyday communication such as 'I am hungry'. It can also be programmed for special situations: for example, Cinnamon uses it to interview support staff by pre-programming the questions that she wants to ask.

Source: Your Place to Live, Housing Options 2004

4.2 Facilitated communication

The assumption that many people with a learning disability, and particularly those with complex needs, cannot read or recognise letters is the main reason that there are not many people with a learning disability using communication aids such as a Lightwriter to communicate more complex thoughts and information.

A method called facilitated communication was developed in Australia in the early 1980s by Rosemary Crossley (who was the subject of the film based on a true story, "Annie's Coming Out") to support people with profound learning disabilities and autism to use more sophisticated electronic communication aids. Facilitated communication involves a facilitator physically supporting a person to use the keyboard and type by supporting either their fingers, wrist, lower arm, elbow or shoulder. The method teaches a person who lacks co-ordination or dexterity to focus on the letter keys, and works towards withdrawing the physical support as much as possible. This will often, but not always, involve teaching literacy and word recognition.

There has been much controversy surrounding this method because of the fear that the content of the communication comes from the facilitator rather than the person themselves. However there are many examples where this has been tested and there are remarkable cases of people, considered to have profound learning disabilities or severe autism, being able to communicate their inner thoughts and write poetry and essays with the help of facilitated communication. There is more information about facilitated communication at www.contactcandle.co.uk.

Many people with a learning disability are prevented or discouraged from entering into a supported living setup because it is assumed that they lack capacity to enter into tenancy and mortgage agreements. The use of Facilitated Communication is one way to support some people to communicate consent and capacity to direct the way they choose to live.

Case Study

Aime uses a facilitator to help him use his Lightwriter. Anyone meeting Aime for the first time could easily assume that because he does not speak, that he has nothing to say. Aime has been assessed as having severe learning disabilities and it is likely that without the determination and commitment of his parents, he would be leaving school to spend his days in the special care unit of a day centre – his story is featured in section 6.

The following is an actual conversation that Aime had with a facilitator called Marion by using his Lightwriter:

A: I go red in the cheeks because I am hot

M: Is that the only reason?

A: Y

M: Do you ever get stressed?

A: Yes, when I try talking to people

M: How could they help?

A: It would help me if people gave me more time to talk

M: Anything else stress you?

A: No

A: Yes. I need people to understand that I feel tired of people thinking I am terribly pretty but that I don't understand language. I think they are people. Think people try hard to do people kind things.

M: Do you mean that people do their best for you by helping?

A: Only Papa

M: How do you feel about how Peter (a support worker who Aime gets on very well with) lets you get on with things?

A: I like Peter's personality

M: Do you mean you like the way he treats you by letting you do things for yourself

A: Yes

4.3 Using ICT for communication

Perhaps the biggest benefit of Information and Communication Technology (ICT) for people with a learning disability is in the area of communication. Using a word processor to produce letters means that the individual with learning disabilities can produce an end result which is as good as that produced by any other person, just as sending an email is a very 'anonymous' way of communicating with others and the sender is not judged on his/her intellectual ability.

There are many special programs written to help people with learning disabilities communicate more effectively but there are also many features within mainstream programs such as those in Microsoft Office programs which can help those with poor literacy skills and short term memory problems. Some of these are listed below.

4.4 Using features within MS Word to support communication

Autotext
One of the most useful features in Word which is very under-used is Autotext. This allows the user to save text and recall it with a short name. This can be one word or a complete paragraph. Imagine how irritating it is for someone who has great difficulty in typing to type his address every time he writes a letter. By using Autotext this is only necessary on the first occasion he needs to type his address. The user first types the text and formats it (in our example it will be the user's address) to appear in a particular font in a predetermined position on the page (e.g. in the centre of the page). Then the text is highlighted and Autotext selected from 'Insert' on the menu bar. When selecting 'New' the user is prompted to give a name to the highlighted text. In this case they may use the abbreviation 'add'. The next time the user wants to insert his address into a document all he has to do is type 'add' and press the Function 3 (F3) key. There is no end to the things that can be stored in this way – think how easily people's names can be added to documents, or the user's favourite personal ending to his letters, or the name of the day service he attends.

Autocorrect
Most of us who use Word regularly are aware of the program correcting spelling mistakes as we type. The later versions of Word are more sophisticated and it becomes harder to type words incorrectly! However, there are always some words we spell wrongly consistently. For example if someone mistypes a word such as college incorrectly as colledge then they (or their tutor) can add this to Autocorrect (found under Tools on the menu bar) so that the word is automatically corrected when misspelt, avoiding those wiggly red lines underlining words in the document!

Text and Background colour combinations
For some people using the default colour combination of black text on white background inhibits their ability to read the text. Other colour combinations are easier on the eyes and these can be selected within Word. However, one combination, white writing on a blue background can be selected as the default very easily. The option can be found under Tools'>'Options'>'General' and selecting 'Blue background, white text'. One advantage of this is that when printing out documents the resulting document is the standard black text on whatever colour paper is in the printer and the user does not use up all the blue ink!

4.5 Other software

Writing With Symbols (from Widgit Software Ltd www.widgit.com)
This is a word processor which uses symbols to support text. Words are automatically illustrated as you type. A single key press can show you the alternatives for any particular word, and you can easily change the symbol set you are using. It is easy to make symbol materials and great for beginner writers. There is a pictorial spell checker in all of the sections. There is an integral speech facility. The program speaks as you type (letters, words or sentences) or you can hear the writing spoken afterwards "on demand".

Another feature of Writing With Symbols is the grid maker. Using grids you can make a vast range of teaching and communication materials including time tables, rotas, worksheets, communication books and games. Grid cells can have single words, symbols, or symbol sentences. You can vary the layout to suit your task, with either regular or irregular cells. For those people who cannot type words themselves there is another very useful feature. People who want to write using symbols or text can simply click with a mouse or switch in a grid cell. A grid cell can have letters, single words, pictures or complete phrases. Other cells can have commands or controls, such as delete, new paragraph etc. A set of grids (called an environment) can be linked to give access to large relevant vocabularies for individual or group use.

Communicate: In Print (from Widgit Software Ltd www.widgit.com)
In Print is a flexible symbol-supported desktop publishing package for creating books, worksheets, newsletters and posters**.** Communicate: In Print 2 is a new version with a complete set of coloured Widgit Rebus Symbols in addition to the black and white symbols and other pictures supplied with the program. This an excellent program for people of all levels of ability. It is really simple to import photographs to use for a whole variety of different activities.

Communicate: Webwide (from Widgit Software Ltd www.widgit.com)
This new software program makes browsing the web more accessible to people who find text difficult. You can see websites in normal view, in simplified layout or with symbol support; with full speech support in any view. You can click on the view button to see any web page in your preferred style and also set font details and background colours to suit your preference. You can hear the pages read with speech synthesis.

Text-to-speech software
For people who cannot read text well and need support then text-to-speech software may be a useful tool. There are a wide range of these on the market such as Penfriend and TextHelp's Read and Write. These are quite sophisticated programs which offer a range of features such as word prediction. However, taking time to search the Internet can be cost effective as there are many programs which can be downloaded free of charge. One of these is a text-to-speech program reader from ReadPlease (ReadPlease 2003 from www.ReadPlease.com. This reads any text you see on your screen.

4.6 Using multimedia features

Computers can support communication by means other than the text or symbols. Many people with severe learning disabilities are being supported to make choices using the multimedia capabilities of modern computers. People can be supported to make choices using graphics. These can be digital photographs of familiar objects, people or places; resources on the Internet are infinite, if you do not own a digital camera. Using Google

Image Search will produce photographs of just about anything! If these are imported into an authoring tool such as PowerPoint then they can be used with sounds to make it more appealing to the user. These sounds can be the person speaking themselves, or (for those that cannot speak) recording them laughing or humming a tune can be very empowering and allows them to communicate in their own special way. This is a very simple process using the Import Sound feature of PowerPoint. Sounds can be added to photographs to give them more emphasis. There are many websites from which sounds can be freely downloaded. For example if someone wants to show their favourite holiday photograph adding the sounds of seagulls can add interest to it. Websites such as www.findsounds.com have a huge range of sounds which can be downloaded.

For those people with learning disabilities who are unable to communicate in any of the ways already described above using video can be a very good means of communicating. This can be extremely powerful at a review meeting in which the person with learning disabilities rarely participates. Showing short video clips of the person in a variety of situations can show how they communicate with others, respond to other people or join in group activities. There are now many software programs for beginners using videos such as Microsoft Media and they can then progress to more complex programs such as Ulead Video Studio or Pinnacle. However a cheaper option is a small hand held digital movie camera called Digital Blue Movie Creator. It can be bought from many suppliers (see Inclusive Technology www.inclusive.co.uk) for under £100 and comes with its own easy to use editing program.

A method using digital photography and sound recording, Photovoice www.photovoice.org works with people to photograph the world from their point of view, so rather than the person being the subject of the photography, they become the photographer. Photovoice can be used to help individuals document how they see the world and use this to teach professionals about what they want and need, Photovoice has also been used as a powerful tool to inform policy development in learning disability services.

4.7 Assistive hardware

There is a large range of hardware available to support people with a disability to use ICT equipment more easily and effectively. Examples are overlay keyboards that sit on existing keyboards with more accessible and easy to read keys, touch screens, roller ball mouse and switches. There are many good suppliers of this equipment, and the charity AbilityNet is a good place to start on advice for the best equipment for specific types of needs. www.abilitynet.org.uk

4.8 ICT in supported living

ICT is being used increasingly in day services and colleges for people with a learning disability. It is less common for people with a learning disability to own a computer at home and use it to live more independently. Many people with a learning disability find it difficult to keep in touch with friends that live around the corner, let alone family and friends that live further away, resulting in isolation and loneliness even if they do share with others. Many people with a learning disability also find it difficult to contact professionals and others involved in supporting them directly, and this can result in people not getting the help they really need.

Having a home computer and having access to the internet, email, digital cameras and webcams can enable people to stay in touch with family and friends, make new contacts,

keep in direct contact with care managers, advocates and other professionals, do the weekly shopping, manage a bank account and pay bills. People with a learning disability can learn to use ordinary email and internet software, particularly if settings are adapted for the person's individual needs such as good colour contrast, large font and icons and placing regularly used icons in easy view. These can be used alongside symbols software and text to speech software to help the person with any reading difficulties. Professionals such as care managers rely on face to face contact with their clients and this time is usually restricted because of the large workload of most professionals. Email has transformed our working lives in how we can make rapid communication with other colleagues, make group decisions and share documents without necessarily having to meet. This same principle could apply with some people who have a learning disability who may benefit from more regular, but less intensive contact with professionals.

Netta

Netta lives in her own flat in an extra care scheme for older people. She owns a PC and is connected to the internet. She has regular contact with her care manager and other people who support her by using email. Netta used email to complain about her inaccessible kitchen –her regular email correspondence with her care manager and OT made sure that they helped her to get a new kitchen without her having to wait for professionals to make contact with her.

4.9 Telecommunications

Telephones

People with a learning disability can lack confidence in using a telephone. This can hinder an individual's ability to carry out everyday transactions such as making a doctor's appointment, contacting friends and family and dealing with an emergency situation which in turn makes the individual less independent.

There are telephones that are easier to use for people with a learning disability with features such as big button dialling, amplification of the individual's and the caller's voice, memory dial with symbols or pictures on buttons and hands free function. BT also have a telephone for ordinary use that can be used with their pendant and emergency response service.

Dialogue P300 Photo Phone

This telephone has nine quick dial buttons where a photo can be slotted in of family, friends and supporters. This model is only available in the United States. This phone can be purchased on the internet at: www.nfss.com/ dip3phph.html
It will cost approx. £26 but will require a North American phone line adapter.

BT Big Button Phone

Also comes in cordless style. It can be purchased from £25 from www.shop.bt.com/invt/ caw111

BT In Touch Careline Phone

It can be purchased for approximately £150 from www.shop.bt.com/invt/ cay224

Mobile telephones

When researching the practical use of various assistive technologies for people with a learning disability, we heard from many people that the technology that has the greatest impact on the lives of people with a learning disability is the mobile telephone.

Mobile telephones have given people who feel unsafe when going out greater security as they are able to make contact with family and supporters wherever they are and get advice and help. Mobile telephone use has grown greatly within the general population; most people own a mobile phone and would probably find it hard to get by without one.

Many people with a learning disability do not use a mobile phone and this is likely to be for similar reasons to ordinary telephones – they do not have the skills or confidence to use a telephone. For those people with a learning disability that do have a mobile phone, there may be difficulties because of the cost of calls and the complexity of most mobile phones.

There is a great deal of choice when buying a mobile phone, with various tariffs and special deals, and this can be confusing for most people. There are reputable mobile phone retailers who will help make the right choice about the mobile phone provider and deal according to individual use. The handset is down to personal taste but there are some features that may make a mobile phone easier to use such as the following:

- Good contrast and colour.
- Separate numbers.
- Voice activated dialling.
- Larger size.

Two mainstream mobile phones that are particularly easy to use are the Nokia 1100 and the Vodafone Simply.

Another mobile phone that may be good for some people with a learning disability is the Silverphone. It has been designed specifically for older people or people with a disability that find it difficult to use an ordinary mobile phone. It has no keypad but has three buttons in green, red and blue which store three numbers and pushing the red button twice will go through to the emergency services. This telephone can also be used to programme reminders such as 'time to leave to get the bus' and the user can respond that they have the reminder by pressing a button. If the person does not respond to the reminder, the phone can be set up to alert a family member or supporter.

There are also mobile phones that look like a wrist watch that may have particular benefit to people who lose their mobile phone easily – but these have the disadvantage of smaller buttons.

Nokia 1100
From £19.99 for Pay as You Go from www.amazon.co.uk

Vodafone Simply
From £49.99 from www.amazon.co.uk

Silverphone
From £139.99 from www.silverphone.co.uk

GPS locator phone
Does not yet retail in the UK but is coming soon www.3g.co.uk

GPS Personal tracker
Approx. £640 from www.gpsw.co.uk/details/ prod1859.html

4.10 Global positioning system (GPS)

Some mobile phones have Global Positioning System (GPS) which is technology that enables a mobile phone to be located or for a mobile phone to give its exact location if, say, the owner is lost. This technology has benefits for people with a learning disability in that if a person wants to go out independently, but there is a risk of getting disorientated or lost, a family member or supporter would be able to locate the person easily and give support.

The GPS locator phone is a particular model that can be used to locate the user from the internet or any telephone by a carer or family member, 24 hours a day. It also has a panic button that goes directly to emergency services, and a programmable button that direct dials a carer/family member.

There are also devices that simply enable a person to be tracked that do not have a telephone function. A GPS personal locator can track movement over the Internet of the person carrying it and has a panic button for the user in case of emergency. The GPS personal tracker has a panic button that will send an emergency text message to any ordinary mobile telephone, which states the person's location, time and date.

There are also companies offering a mobile phone tracking service that can track ordinary mobile phones with the owner's permission; this does not require any special equipment but does require a subscription to the service. Several companies can be found by doing a search on www.google.co.uk

This is a little known area in general and is only used widely with children in the USA. GPS technology is developing and advancing rapidly in the UK and there is likely to be development of tracking devices for vulnerable adults. There will be a big question mark about the ethics of tracking a person who cannot give consent but the reality is that most people who are able to go out alone without someone to support them are likely also to be able to give or withdraw consent to be tracked.

Communication is about people

There is no doubt that AT is a valuable way to assist and enhance communication for people with a learning disability – in many cases it will make a vast difference to a person's quality of life and enable people to live more independently. What is also clear is that AT will only be successful in helping people with a learning disability communicate where there is good support to learn how to use the various devices and tools. In other areas of AT, the need for human support can lessen or be removed with the use of the technology, but with AT to assist communication there is likely to be a need for increased support and skills level of a supporter.

United Response, a large voluntary sector organisation that supports people with learning disabilities has a communication strategy that focuses on listening. The strategy says "to listen to people, we have to know how each person communicates, and be able to communicate with them", and "effective communication is, therefore, a gateway to our providing the desired and required support".

People with a learning disability could be using the best and most sophisticated technology for communication but if people and services do not make it their job to listen and respond to what is being communicated then the best communication technology can become redundant.

Chapter 5   Paying for Assistive Technology

In this chapter we review how different types of AT can be afforded.

For many individuals and care providers the funding of AT was a mystery. For those who had succeeded in getting larger environmental control equipment it had often been a challenge, sometimes without entirely satisfactory outcomes for long-term provision. The funding of basic telecare packages was generally much easier. We found in practice that a wide variety funding sources are used. A new grant being given to Social Services specifically to fund telecare came on stream in April 2006 and this may provide at least a short-term mechanism for meeting capital costs (see Appendix 1).

5.1 What are we paying for?

There are different types of expenditure.

Capital:
- Infrastructure costs – for example hard wiring electrical sockets used to power environmental control systems like door and window openers.
- Telecare equipment – for example an alarm unit and an array of sensors.
- Environmental control equipment – for example vertical storage with shelves adjustable electronically for access from a wheelchair.
- Stand alone equipment.

Revenue:
- Monitoring service if used.
- Maintenance of installation.
- Response staff/carers.

The different types of expenditure lead to different funding sources. This can be one of the complexities. However, within limits, it is possible to turn "capital" expenditure into revenue. Typically this is by a Central Control monitoring service or a manufacturer leasing or renting equipment to users. Capital items will depreciate and funding for replacement must eventually be found as well.

5.2 Revenue Sources

Housing Benefit

The majority of people with a significant learning disability are eligible for Housing Benefit if they rent their home. A payment of 100% Housing Benefit is automatic for anyone on Income Support. Housing Benefit is a benefit that pays for:

- Pure rent on the property, including management and maintenance.
- A limited number of items paid through a service charge which are necessarily incurred in occupying the property.

Schedule 1 to Regulation 10 of the Housing Benefit regulations (SI 1987, No 197) said at paragraph 1(c):

"(c) charges in respect of the provision of an emergency alarm system are ineligible **except where such a system is provided in accommodation which is occupied** by elderly, sick or **disabled persons** and such accommodation, apart from the alarm system, is either:

i.   Specifically designed or adapted for such persons, or
ii.   Otherwise particularly suitable for them, having regard to its size, heating system and other major features or facilities"

In 2003 the Housing Benefit Regulations were amended so now paragraph 1(c) of Schedule 1 simply says:

"(c) Charges in respect of the provision of an emergency alarm system are ineligible"

Source: Housing Benefit (general) Amendment Regulation 2003, SI No. 363

The implication of this is that a community alarm system was explicitly fundable by Housing Benefit in the case of property occupied by disabled people. However, when Supporting People was introduced this responsibility along with 'support and counselling' fell to the new Supporting People grant regime. So in principle, Supporting People grant should now meet the revenue costs of telecare.

There is however a question of what can still be covered by Housing Benefit. What are eligible service charges? The rules for what the benefit system can pay are the same whether people are tenants or leaseholders. The difference is that (shared ownership aside, where the housing association can agree to be liable for maintenance in the rent and put costs into the rent) if people are leaseholders, they can get help towards service charges either through income support or pension credit, not via Housing Benefit. Income Support and pension credit look at service charges as eligible housing costs (as long as they are eligible service charges) and include them in calculations when assessing people's entitlement.

These means-tested benefits may cover:

- Property based sensors (on the basis they are necessary to provide adequate accommodation).
- Access costs for example keyless locks.
- TV – but only for ordinary UK channels and not satellite dishes or decoders. You can only get cable TV covered if it is the only practicable way of providing ordinary domestic channels.
- CCTV.
- Entry phones.
- Communal telephone costs (i.e. not individual phones in rooms/flats).
- Fire system maintenance.

What is specifically excluded includes:

- TV licence fees.
- Provision of an emergency alarm system.
- Medical expenses.
- Nursing and personal care.
- Counselling/support.
- Other charges not connected with the provision of adequate accommodation not included in the first list.

Housing Benefit administrators can reduce the amount of service charge they base entitlement on if they feel that the cost is unreasonable, using local comparators. Income Support has similar rules if they feel costs are 'excessive'.

The conclusion in relation to much of the welfare benefits guidance is that it has not really kept up with the change in telecare beyond basic alarm systems. In particular we found Housing benefit frequently funded telecare that was primarily used to provide security for residents.

There is some limited scope for spreading the cost into service charges, as long as they are global 'accommodation' costs as opposed to specific individual requirements and interventions.

Supporting People grant

In principle Supporting People grant paid by local 'Administering Authorities' (usually the local authority with Social Services responsibility), can pay for AT. Supporting People grant is to fund 'housing related support' for vulnerable people. Supporting People grant has replaced the element previously funded through Housing Benefit. Many Supporting People five-year strategies explicitly refer to increased use of AT. For example,

"In addition, further development of community alarm services, including new technological advancements in passive alarms, will be supported as part of an integrated, person centred care and support package."

Source: Cumbria Administering Authority

Care providers in our case studies were using Supporting People funding; but the limitations on the overall Supporting People budget (real term cuts) and difficulties in getting Supporting People for new clients, combined with a perception that some people with learning disabilities are already receiving generous packages and ceilings placed on total package costs, made those in our case studies wary of relying on Supporting People. Nevertheless this should be a key source of revenue funding.

The Supporting People rules and guidance are complex. They seek to distinguish between what is properly a 'housing' cost from a 'support' cost and also not to stray into funding 'personal care', while still permitting some flexibility.

Guidance in relation to telecare is as follows:

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Supporting People grant for telecare

- The costs of purchase, installation and maintenance of hard-wired systems should be allocated to housing management budgets.
- The costs of purchase, installation, maintenance and monitoring of building safety systems such as fire alarms and communal access control systems should be allocated to housing management budgets.
- The cost of purchase, installation and maintenance of dispersed alarm systems should be allocated to Supporting People budgets.
- The cost of purchase, installation and maintenance of personal safety and telecare systems such as an individual's CO, flood or temperature detector should be allocated to Supporting People budgets.
- The costs of monitoring all calls from social alarm and telecare systems should be allocated to Supporting People budgets.
- Calls from fire panels and hardwired smoke detectors signalling through a social alarm group scheme would be treated as building safety systems and their costs charged to the housing management account.
- The costs of professional response (e.g. mobile warden) to social alarm and telecare system calls should be allocated to Supporting People budgets.

Source: The Association of Social and Community Alarm Providers in consultation with ODPM.

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Those already receiving Housing Benefit are not subject to a means test for Supporting People. Note that an element of staff-based response to an event can be covered by Supporting People. In practice, for people with learning disabilities in our case study visits, Social Services were usually meeting the direct staff costs of responding as part of the care and support package for each individual.

Welfare Benefits

An individual in receipt of welfare benefits can choose to use some of those benefits to buy a package of telecare. Most people with a learning disability living in supported housing (or at home) are eligible for Disability Living Allowance (DLA) at some level. This is a non-means tested benefit. Current levels 2005/06 are:

Disability Living Allowance

Care component	£
Highest rate	60.60
Middle rate	40.55
Lowest rate	16.05

Mobility component	£
Higher rate	42.30
Lower rate	16.05

The examples, based on leasing a package of equipment and a monitoring service including an emergency mobile response, cost £5 - £8 per week. On this basis at least a basic package of telecare should be affordable by all, even if Housing Benefit or Supporting People funding is not available.

Direct Payments

Direct Payments are available as a right under the amended Direct Payment Act 1996. This means someone with a learning disability could receive cash to arrange their own package of care. This can include AT provided it meets an assessed need.

There are pros and cons of opting for a Direct Payment. It will usually imply an amount of support to actually administer and account for the payment to employ personal assistants, recruit and supervise personal assistants. This is not consequently likely to be suitable or appeal to everyone. It is however, another route to affording a tailored package of AT.

Individualised Budgets are based on a similar principle as Direct Payments in that the individual has control of how their support is arranged. They differ in that the person is allocated a sum of money for care and support according to a local banding and they have the choice of employing staff directly, or employing one or more care providers and/or purchasing a place in a supported housing scheme. The funds from an Individual Budget can also be used to purchase AT.

Direct Payments are not additional money. The funds used to make payments come from Social Services care budgets. Direct Payments are simply a different way of arranging and delivering care, which give some people and their families greater control over how a package of support and care is provided and who provides care.

Social Services

Where a disabled individual has had an assessment of care needs the local authority becomes responsible for meeting those needs. This may be by placement in residential care, via an adult placement, use of supported living, providing help to relatives acting as carers or in other similar ways.

For most of those not supported by relatives Social Services will be arranging for a package of care to be provided either by contracting with a 'care provider' organisation or directly through their own staff. The former is increasingly common.

What this means is that once a Social Service authority has accepted it has a duty to provide care it can choose to arrange at least some of this by using AT. For most people with learning disabilities living independently this in turn means that the (expensive) ongoing staff element of costs of responding will be met by Social Services.

As a number of the examples illustrate, from Social Services perspective, switching some of the package of care and support to telecare can make good economic sense.

5.3 Capital

Housing Associations

Housing associations are now the only significant source of new social housing to rent or buy on low cost home ownership terms like shared ownership or homebuy.

Where property is newly built **infrastructure** costs can be incorporated in the construction and part of the cost is consequently met through Social Housing Grant paid to registered associations (and occasionally under new regulations to private developers of social housing) by the Housing Corporation.

Retro-fitting existing property is more problematic and costs can be high. The principle source of funding found in case study visits was retained grant re-invested in the properties.[1] This **cannot** however under Housing Corporation rules be used to purchase **equipment**.

Community Equipment Service – Section 31 Funding

In 2000 the Audit Commission produced a critical analysis of the way the NHS and Social Services went about providing equipment to physically disabled people.

The Commission said there were unacceptable variations in services, senior managers neglect equipment services, which are under-resourced and poorly planned. The Commission recommended that specialist rehabilitation centres should be created, that NHS and Social Services equipment stores should be combined, and that better services be included in national priorities guidance and the national framework for older people.

Source: Fully Equipped, The Provision of Equipment to Older or Disabled People by the NHS and Social Services in England and Wales. Audit Commission 2000.

This was followed by a similarly critical report from the Audit Commission two years later; *Fully Equipped (2002)*. Since then considerable progress has been made to offer an Integrated Community Equipment Service (ICES) with local authorities and health collaborating. There are 186 Equipment Services across the country. Progress in creating these combined stores varies around the country and some are more up to date and organised to provide AT than others.

Definition of community equipment

The Centres can provide a wide range of equipment for daily living such as shower chairs and raised toilet seats (usually provided by local authorities) and nursing aids (traditionally the province of the NHS). The list however is longer. It includes, but is not limited, to:

- Minor adaptations, such as grab rails, lever taps, improved domestic lighting, and improving the use of contrasting colours.
- Ancillary equipment for people with sensory impairments, such as flashing doorbells, low vision optical aids, text phones and assistive listening devices.
- Communication aids for people with speech impairments.
- Wheelchairs for short term loan, but not those for permanent wheelchair users, as these are prescribed and funded by different NHS services.
- Telecare equipment such as fall alarms, gas escape alarms, and devices that detect when vulnerable people wander out of the house.

Source: DH Policy Guidance

The equipment should be provided free. Both the NHS and Social Services were given additional money over three successive years to bring about an improved service.

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[1] *When registered housing associations sell property for example under rights of tenants to acquire their home which has previously received grant from the Housing Corporation (or in the past occasionally local authorities), the proceeds of sale can be retained by the association. Some of the receipt may have to be used to repay the association's mortgage on the property. The balance can be kept. It must however be used to develop additional housing.*

Community Equipment Services and Charges

Any item of community equipment which a person (or their carer) is assessed as needing as a community care service, and for which the individual (or their carer) is eligible, is required to be free of charge. All minor adaptations costing £1,000 or less (which includes the cost of buying and fitting the adaptation) are required to be provided free of charge. Councils retain the discretion to make a charge in relation to minor adaptations which cost more than £1,000 to provide.

Services should set their eligibility criteria in line with Fairer Access to Care Services (FACS) guidance. Assessment and provision of services should always be needs-led and outcome-focused. Any service carrying out the functions of providing community equipment as defined in the regulations is required to be provided free of charge, regardless of the operational name of the service.

Source: Department of Health, Local Authority Circular (2003) 14, June 2003.

The equipment is technically loaned to the person who uses it. One of the keys to achieving a better 'one-stop shop' service rather than two parallel services was the Health Act 1999, which removed barriers to Social Services and Primary Care Trusts pooling budgets and integrating services. The new flexibilities are commonly referred to as 'Section 31'.

The government encouraged the involvement of housing in the re-development of services and there is evidence that this has happened – at least sometimes.

Wandsworth Community Equipment Service

Contact the Careline Information Centre for Wandsworth for free help and information on equipment (chair raisers, toilet seats etc) and adaptations (hand grips, stair rails etc). Care line is now the single access point for information about equipment and adaptations in the London Borough of Wandsworth. This integrated equipment signposting service gives access and eligibility information for hospital, community and Council Services.

www.careline.org.uk/Equipment

Source: Wandsworth Community Equipment Service

Some authorities have in addition established a distinct Environmental Control service, for example Kent and Medway NHS (see caption box overleaf).

Environmental Control Service

An environmental control system helps disabled people operate electrical appliances and some other equipment in their homes. They do this by using various types of switches, including those operated by movements of the hand, foot, chin, eyes or mouth. Some of the more common uses include:

- Releasing door locks.
- Lighting.
- Using the telephone.
- Controlling television and hi-fi units.

The environmental control service employs an OT who provides equipment and does follow up work. Engineers based with the service give technical advice to the OT.

The NHS pays for the equipment provided and the local council's Social Services Department generally funds the costs for any electrical or carpentry work required. There are no costs to the individual user.

People can access the service via:

- Written referral from medical professionals e.g. community OTs.
- Self-referral endorsed by a medical professional.

Source: Disablement Services Centre, West Kent NHS and Social Care Trust

It appears the community equipment stores could become a core source of the physical equipment. From our case studies the reality appears to be that, as yet, few people with learning disabilities are actually finding their way to this service for a comprehensive package of AT.

5.4 Disabled Facilities Grant (DFG)

DFGs are grants to help older and disabled people adapt housing in order to make it suitable for independent living. The grants are administered by the local housing authority. This might be a District or Borough Council or a City Council, not Social Services, although very occasionally Social Services carry out the assessment on behalf of the housing authority.

These grants are commonly used to carry out adaptations to the building such as installing a bathroom on the ground floor or modifying a kitchen; this can be up to £25,000 in England. The grant is mandatory; if you meet the criteria you have an entitlement but this is subject to a means test. A disabled person on Income Support or Job Seekers Allowance will not normally have to make a contribution.

In order to qualify a person must be disabled under the Housing Grants, Construction and Regeneration Act 1996. A person is disabled if:
- Their sight, hearing or speech is substantially impaired.
- They have a mental disorder or impairment of any kind.
- They are physically disabled by illness, injury, impairment present since birth, or otherwise.

This encompasses people with a learning disability, whether or not they also have a physical disability.

An applicant for DFG may either be the owner or the tenant of a property.

Published examples of works suitable and eligible for DFGs include:

- Providing suitable bathroom and kitchen facilities that you can use independently.
- Making your home safe for you and people living with you.
- Adapting heating or lighting controls to make them easier to use.
- Improving the heating system in your home to make it suitable to the needs of the disabled person.

In one of the case studies of a two-tier authority Social Services had agreed with District Councils that installation of AT was eligible for DFG. This could therefore be the route to funding the installation of more substantial environmental control systems.

Points to note:

- An OT's assessment is commonly a prerequisite for grant approval.
- Delays in giving grants are widespread but there are statutory limits to waiting times.
- In a court case (R V Birmingham City Council exp partner Mohammed, 1998) quoted by Age Concern, it was decided local housing authorities should not take into account their financial resources when deciding to approve a DFG.

5.5 Preventative Technology Grant

This is a new grant given to Social Services authorities to pump prime the growth of AT. Details are provided at Appendix 1. In setting out details of the issues to be considered by authorities in using the grant the Department of Health re-iterated that those who have a community care agreement are not expected to pay but others can be asked to contribute to costs.

Charging

Where, as a result of a community care assessment, telecare equipment is provided by a local authority as an aid for the purpose of aiding daily living, it should be provided free of charge.

A charge may be made for the service elements (revenue) of telecare. Charging should be in line with local Fairer Charging and Fairer Access to Care Services (FACS) policies.

Where it is part of the local strategy to provide telecare packages to people who are not assessed as requiring them, for instance as a preventative service, a charge can be made for the equipment and the service (revenue) elements. In these instances the FACS means test can be used in the same way as for Supporting People charging assessments.

Source: Building Telecare in England, DH, 2005.

Funding Telecare Installation					
	Revenue			Capital	
Source	Monitoring	Maintenance	Staff response	Infrastructure	Equipment
HB	Some	Some	✗	✗	If lease / rent
SP	✔	✔	✔	✗	If lease / rent
Benefits / Own Resources	✔	✔	Possible, but costly	Possible	If lease / rent
Direct Payments	✔	✔	✔	Possible	Possible, particularly if lease / rent
S.S. / PCT	✔	✔	✔	✔	✔
Equipment Centres	✗	✗	✗	✗	Loan basis
Housing Association / Social Housing Grant	✗	✗	✗	✔	✔
DFG from LA	✗	✗	✗	✔	✔
Preventative Technology Grant	✔	✔	✔	✔	✔

This is only an approximate guide to funding. In practice, possibilities appear to vary locally! The list is not exhaustive. There may be charitable, discretionary trusts or other sources. Occasionally, relatives will fund.

Benefits include DLA, so many people with a disability can afford telecare when equipment is loaned along with a monitoring service if they choose this.

Chapter 6   Changing lives with Assistive Technology

In our gadget and technology obsessed world, it would be easy to get excited about the use of some of the technology to support people with a learning disability for the sake of using technology. When we are used to hearing about or using technology that makes profound changes in our everyday lives, such as mobile phones, digital cameras and email, we can forget about those gadgets that merely make what can seem like small differences.

For many people with a learning disability it is the small things that can make a big difference, such as a pendant, a picture phone or a mobile phone; so why do so few people use them? There is also the 'up-to-the-minute' and cutting edge technology that can make the most profound changes in people's lives; like the mother who does not now have to be alert 24/7 to make sure her son doesn't spend day and night in a constant state of anxiety in search of food, or the young man who doesn't speak, but can now share his innermost thoughts and feelings.

This chapter gives real life examples of how AT, both big and small, can change the lives of people with a learning disability. Some of the case study examples use the individual's or carer's own, personal explanations.

6.1 Sandra Wood

Sandra lives in her own flat in a scheme of supported cluster flats – her landlord and support provider is Southdown Housing Association. Sandra moved into her flat in January 2005 after living in a large residential care home.

When Sandra first moved into her flat she had never really spent time alone before and this was a worry for her and those supporting her, particularly as Sandra has a physical disability and has occasional falls.

Southdown also had another tenant living next door to Sandra with a similar issue. They did not want to compromise Sandra's (or her neighbour's) independence by spending too much time in her flat or by having to make regular checks, which can be intrusive. They decided to try out a pager system so that in the event of a fall or illness, when staff were not providing direct support, Sandra could contact them using her pager.

The pager they use is made by Scantronic and cost approximately £80. It is connected to a pager held by staff. If Sandra presses the button of the pager the staff are alerted and shown where the call is coming from. Sandra wears the pager around her neck or has it next to her on a coffee or bedside table.

When Sandra started using the pager she had difficulties in understanding exactly what it was for and used it for non-emergencies, such as asking for a cup of tea at 1am. It was new for her support staff too and they were not clear about how to support Sandra to use it well.

Between them, they have now established clear guidelines for use. The only real problem with the pager is that the button is not easy to press and this can present problems for people that do not have full dexterity.

For Sandra, the pager gives her the added confidence and security to live more independently.

6.2 Netta Jenkins

Netta lives in her own flat, in an extra care scheme, managed by Chichester Diocesan Housing Association. It is a scheme for older people generally but includes older people with a learning disability.

All of the flats have been fitted with video door entry and a Tunstall alarm system. This is typical for schemes specifically designed for older people to live more independently.

The video door entry allows Netta to see who is calling for her at the entry to the flats and therefore make an informed decision as to whether she wants to let the caller in. This is operated through Netta's television and is as easy as turning the set on and selecting a channel with a remote control.

A common problem when people who are vulnerable live more independently is the risk of financial exploitation through being coerced into signing up for credit cards, utilities and double glazing that they do not want.

Netta lives in a scheme where there is 24-hour staffing so there is less risk of unwanted callers. For Netta, the specific benefit of having the video door entry has been that she does not have to get to her front door to screen callers and let them in because she knows exactly who it is coming up, she can remain in her living room and open the door remotely. This has been beneficial because of the difficulty Netta has in moving about her flat at speed.

Netta uses her Tunstall alarm to contact support staff whenever she needs help outside of her ordinary support times.

6.3 Stephen Stevens (not his real name)

Stephen lives in a small registered care home that is on a site with other small homes. Stephen's service is an Intensive Support Unit (ISU) and is especially for people who have a reputation for challenging behaviour.

Eight years ago, Stephen was regularly leaving his home without support staff knowing. There were many incidents in the community where Stephen, his support staff and the general public were placed at significant risk.

There were also issues of violence towards support staff and visitors, which resulted in low staff morale and a high staff turnover. This in turn had an impact on Stephen and his behaviour which was escalating.

The manager of the service looked to AT to see if this could support Stephen more effectively. The first system installed was a door-activated pager system that would activate within five seconds of the door being open. This sent a visual and sound message to a pager that was carried by a team member. The team member could then ensure that Stephen did not leave his home alone and there have been no further incidents.

A panic alarm was added to the system shortly afterwards following an increase in violent attacks against support staff. This was carried by a team member and activated by the single push of a button which sent a message to the same pager used for the door activated alarm. It has a particular alarm sound which enabled the team member to react quickly without having to check the pager. This has given the team members reassurance when lone working with some service users.

Scope Page Tek Mk2 base units and hand held pager

The pager system has been set up to send two alerts with a gap of ten seconds between alerts. The second alert was added to ensure that team members responded, especially if for some reason they had missed the first alert. The pager system has been subject to a lot of changes over the years with extra doors being added to the system to better support other service users as well as Stephen.

There have been some problems with the system, mainly around the fragility of the pagers. The plastic holders do not last long and so team members end up carrying the pagers in their pockets; this is not an ideal use as staff need to be able to see and hear the messages on the pager clearly.

There has also been much debate within the staff team about the service user's rights to freedom of movement, but this argument has always been outweighed by the high risk to service users and others if it is not used. This debate has made the staff team conscious of how the system is used, and so far it has never been used to restrict the movements of a service user.

The outcomes of using the sensor pad and pager system has been Stephen becoming happier, a 50% reduction in staffing costs because it has reduced the need for 2:1 staffing, reduced staff turnover and a significant reduction in incidents of aggression. One service user uses the system as a form of communication by opening his bungalow door whenever he needs something from support staff.

There are two base units on site and the cost of all of the equipment is approximately £800.

6.4 Oliver Haggarty-Jones

Oliver is 13 years old and has Prader-Willi Syndrome (PWS), a condition that causes an excessive appetite and a subsequent obsession with food. Oliver uses Wrist Care by Vivatec which has been specially adapted to help him manage his obsession with food. Kate Hagarty-Jones, his mother tells their story:

"I am the mother of Oliver (PWS) 13, Ella (10) and Bronte (7). I am writing to tell you about the AT system that has recently been installed in our home and the difference that it has made to our lives.

"To start at the beginning - 13 years ago, when Ollie was born and we received the shattering news that he had PWS. I remember quite clearly amongst the myriad of emotions that we experienced at the time, a determination that, with the benefit of an early diagnosis (three weeks), it would surely be possible to teach Ollie not to take food. We could train him – we could educate him as he became older about the importance of not over-eating and if we were disciplined and consistent then perhaps we might succeed. Looking back, this seems extremely naive, and no doubt was part of a denial about Ollie's condition, but at the time it felt good to have something positive to aim for – to feel that there was a way forward when we felt so overwhelmed.

"It was with a real sense of failure initially then, when about seven years ago I fitted the first cupboard lock. As Ollie became taller and more physically able it was becoming increasingly difficult to rely on my vigilance and to trust him not to take food that he wasn't allowed. Ollie knew then, as he knows now, why his food intake must be controlled – he can and does talk knowledgeably about a healthy diet and is far more informed than many adults! However, the reality is that the obsession is so innate that all the theorising in the world counts for nought if the opportunity for Ollie to take food (without being caught!) presents itself. Although there are times when he will proudly bring me some food that has been left lying around inadvertently by the girls or a visitor, on most occasions, the temptation to eat it is too great.

"And so the number and type of locks multiplied! I realised that, in fact, rather than being a failure, this was a more effective way of managing life with a PWS child - to rely on his willpower and the vigilance of the girls and myself was unfair to him and unrealistic for us.

"However the locks were certainly not a problem-free solution. They are designed to make access to food difficult, but not impossible, and the very fact that it is possible to overcome them provides a temptation. As he has grown, it has proved increasingly difficult to find any that are totally Ollie-proof! Even the magnetic ones present him with the challenge of finding the magnetic key to unlock them. An alarm in the hallway covering internal access to the kitchen was successful briefly, until Ollie discovered that he could crawl under the

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sensor! Bolting the kitchen door was fine until he tried climbing out of the window of another room into the garden and through the back door. And of course, one the big downsides of all these locks and alarms is that they restrict life for everyone in the household and simple tasks become major exercises; popping upstairs to put washing away involves checking where everyone is (particularly Ollie), locking all necessary doors and windows to the kitchen, making sure that no-one is locked outside etc!

"Nonetheless, despite all the difficulties Ollie has done extremely well. He weighs approximately 45kg and, with the help of growth hormone, is 151cm tall. It was during discussions with our OT about finding an effective fridge lock that this enlightened lady first suggested the solution that has changed all our lives. She mentioned a Scandinavian system that has been used in this country primarily in care homes where they have Alzheimer's sufferers. The system requires each patient to wear a wristband which identifies them uniquely and allows a combination of sensors and the computer software to monitor their movement around the home. She wondered whether such a system might be modified to operate in a private household such as ours where knowing the whereabouts of an individual can be vital.

"And so, an arduous process began. Whilst the company, Vivatec, willingly put forward a proposal for a modified version of the technology with Ollie's specific needs in mind, securing the necessary funding proved to be quite a battle. However, after eighteen months we were successful and the system has been installed for just over six weeks. What a transformation it has been for us all!

"It works like this : Ollie wears a 'WristCare', rather like a chunky watch without a face, and there are sensors placed strategically around the house, primarily covering all access to the kitchen. The software to control the system runs from a PC. The moment Ollie crosses the thresholds defined by the sensors, a message is sent to a pager telling me exactly where he is. Unlike other alarms that we have tried, a response is only triggered by the person wearing the WristCare, rather then any other member of the household, cat or dog etc.!

"The immediate benefits are obvious and were as anticipated – I can move freely around the house without having to remember to lock doors as I go, the girls can go to the kitchen to get a drink without having to first ask me to unlock a door, I no longer need to think every two minutes "Where's Ollie and what might he be doing?" In effect the system has become my eyes and ears. That being said, it takes a long time to let go of habits acquired over years of being vigilant!

"However, the overriding, and most unexpected benefit has been for Ollie himself. Not the fact that his opportunities to take food have been restricted, with the consequent positive impact on his weight management – this was what we hoped for. The biggest change has been in Ollie's behaviour: as I said earlier, with all the other preventative mechanisms we tried, there remained the possibility of overcoming them and managing to access food. And no matter how small the chance, if it existed, Ollie would try and take advantage of it. It seemed as if much of his waking time was spent working out ways to "beat the system" or take advantage of a momentary weakness in it – and if he succeeded there were the inevitable confrontations.

"With this system, Ollie knows that the second that he crosses an alarm threshold, I will be alerted; he simply cannot enter an area where he might find food without being detected and because he knows that he will be caught, he no longer tries, nor spends time watching

for an opportunity. As a result he is far happier and relaxed and extremely proud of "the system that helps him". It is as if, at least whilst he is at home, a huge pressure has been taken off him.

"I realise that the Vivatec solution may not be either necessary or appropriate for everyone. It certainly doesn't dispense with the need to teach Ollie how to manage his food intake – much of his life, after all, is spent outside of the home. However, for us as a family and most especially for Ollie as an individual, it has made a tremendous difference to our day to day lives.

"As an additional feature, the system monitors Ollie's physiological activity through the WristCare. This data is displayed on the PC via a series of graphs. In elderly patients, this can be used to monitor the body's activity at night, including incidents of sleep apnoea. The software also includes a threshold to indicate the point at which the body is medically asleep and these periods of proper sleep are defined on the graphs. So far, despite the fact that clearly Ollie does 'sleep', the data indicates that at no point does his brain/physiological activity ever drop below this accepted threshold into so-called proper sleep."
This story was published on the Prader-Willi Syndrome Association website www.pwsa.co.uk

Oliver's story describes how it is possible to make a dramatic difference to a person's quality of life by thinking laterally around how AT might help with a specific problem or situation.

In Oliver's case, he was lucky to have a combination of an enlightened OT working in a local authority that is keen to develop supports using AT and a provider, Vivatec who was willing to adapt existing technology and fund the majority of the costs so that it could be tested, as well as an open minded family.

The total set up costs were approximately £12,000 – the local authority contributed £3000 and Vivatec £9000. WristCare would ordinarily cost approximately £800.

These set up costs may seem expensive but within the context of Oliver's support needs, it is a small amount. Oliver currently receives domiciliary care and is assessed as needing 2:1 support when he goes out of the house. When Oliver eventually does live more independently, he will need less intensive support because of the AT and this will have a big impact on the cost of his support. In addition, Oliver is learning how to manage his condition more effectively and this will have an as yet unknown impact on his support needs when he moves from his family home.

One of the incidents that sparked off the need to use AT was when Oliver ran away from his family home and got on a train at an unmanned station. He was eventually found after an extensive police search which included launching a police helicopter for four hours. The cost was £20,000! This is unlikely to happen again because of the WristCare because essentially, Oliver is 'tagged'. There are many issues around his rights to freedom that are counter to being 'tagged' but in Oliver's situation, this 'restriction' enables him to live in a less restrictive way.

Finally, Oliver says about the WristCare "It helps my Mum and sisters – it's good."

6.5 Joanne Noakes

Joanne lives in her own flat for the first time in her life. She has recently moved from a large residential care home that was closing and had been looking for a place to live for a long time. It had been difficult to find the right place to live because Joanne did not want to share with others and did not want to have support staff in her home constantly. Joanne has Prader-Willi Syndrome and this means that she needs a lot of help to manage her food and eating patterns. Ideally, Joanne did not want to keep food in her house but this meant that staff would need to come in to her house regularly and at times that did not necessarily suit Joanne.

Joanne also has regular falls because of mobility problems and she is unable to get up by herself so this also posed problems in her wanting to live alone.

After a long time searching for the right housing and support, Joanne's care manager found a local supported housing service that was prepared to convert what was an office area into a specially designed one bedroom flat for Joanne. The manager of the service worked with Joanne, her Mum and care manager to work out exactly what Joanne needed to be as independent as possible.

They were able to support Joanne to not keep food in her house by keeping it on site. A pager system has been set up so that Joanne could call staff when she is ready to eat. She uses a wristband instead of a pendant so she can more easily access the alarm when she falls. She is able to tap the face of the wrist band to contact staff.

Joanne has minimal support from staff in the mornings, evenings and weekends and has been able to achieve her goal of living as independently as possible. The cost of the pager and the expansion to an existing pager system was £650.

6.6 Aime Bosc Nikolov

Aime using his Lightwriter with facilitated communication.

Aime is 16 years old and lives in his family home with his mother, Michelle and his father, Cris.

Aime does not use verbal communication and uses a range of communication aids and technology to assist him with communication.

Aime attended a school for children with severe learning disabilities where he received an education that did not stimulate him and he had very limited choices in the content of his education.

Aime's parents recall a time when they went to visit Aime at school during an IT lesson. The room was filled with the best hardware and software yet Aime was sitting uncomfortably in front of the computer screen with his body facing away from it and was not able to focus on using the computer effectively. The learning he was receiving to develop IT skills felt very tokenistic.

Aime was receiving less than one hour of educational input in a six and a half hour day at school so his parents made a decision when Aime was eleven years old, to educate him at home. They had been given information from another parent at the school about a technique to support communication called Facilitated Communication, a method to physically support people who have difficulty with verbal communication and who cannot reliably point on a keyboard. Aime's parents studied to become facilitators and used this with Aime at home. This method is often used with people who have a severe learning disability or Autism and has been controversial because of a concern that the facilitator can either consciously or unconsciously direct the content of the communication.

Aime started by using Cheaptalk, a simple communication tool that is mainly used to answer closed questions e.g. Do you want to go out?

Aime using Cheaptalk.

Since Aime has been home schooled, he has attended a specialist intensive teaching centre, Castle, for four hours per week and has been studying the national curriculum with the help of a Lightwriter. The Lightwriter is a small hand held computer and speech synthesizer that relies on the person being able to spell most of the text they input. The Lightwriter is rarely used by people with a learning disability for this reason. Aime has used pattern recognition flashcards between the age of two to six years old and this has helped him to spell and recognise words.
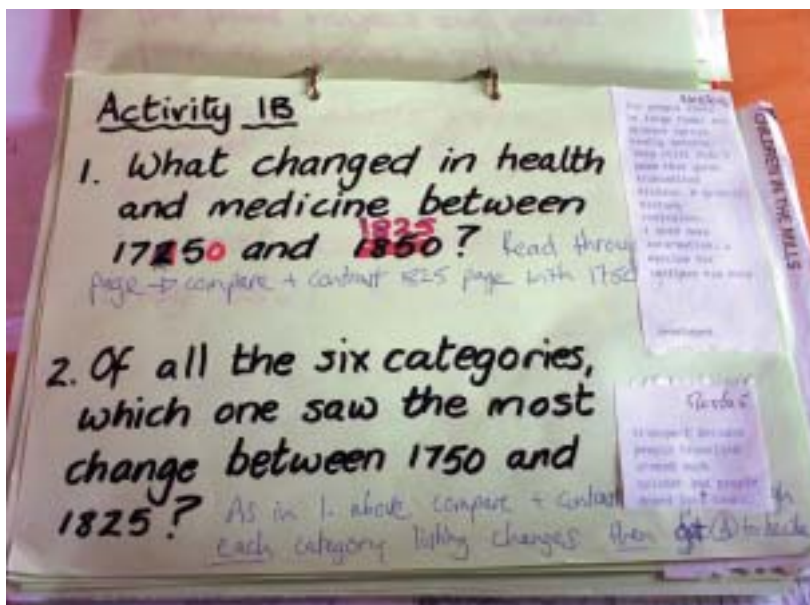
Aime has owned his Lightwriter for nearly four years and now uses it both at home and at Castle for every day communication and for education. He is currently studying the industrial revolution at the same level as his non-disabled peers. He uses the Lightwriter with a facilitator and is slowly requiring less physical support –Michelle feels that on a good day, Aime contributes to 60% of the lesson.

Aime's history lesson with his answers printed with the Lightwriter.

Aime now has a new communication system that he will begin learning called Paceblade. The software program is called The Grid and can be used on an ordinary PC alongside other software. It has a small keyboard and a touch screen and supports Boardmaker, a symbol package.

The benefits

For Aime, the benefits of using AT for communication are immeasurable. Most importantly, he has been able to express his thoughts and feelings and to make his wishes known. As he was growing up he was very passive. It is easy to assume that Aime has a profound learning disability on meeting him and he has become curious, inquisitive and actively seeks information. He enjoys being with people, reading books, watching the news and has a real sense of power and control over his life. Aime has also developed emotionally and is showing much more emotion now than he did when he was younger. Michelle and Cris said that they had no idea that Aime had the type of feelings that he expresses by using the Lightwriter.
Using AT has also led to Aimee getting more age appropriate education where he is able to follow the national curriculum and is stimulated by his learning. At school, his intelligence was measured by his expressive language so there was no recognition that he needed to learn. This is true for countless people who have been labelled with a severe learning disability.

An indirect benefit of using AT is the perception that others have of Aime as a computer user – he is seen as a person who has something to say.

I asked Aime what he thought the benefits of using the Lightwriter were for him – he replied using his Lightwriter "People are just involved in getting my drift – you don't understand".

For Michelle and Cris as carers, AT has not necessarily made life easier and in many ways they feel it would have been easier not to use it. There is a great deal of time, commitment and patience needed to remember to use the devices and remain aware, mindful and engaged and this can require more energy than many carers have.

Problems with AT

With Cheaptalk, there is little likelihood of anything going wrong with it as it is a simple piece of equipment. The only minor problems Aime has experienced have been a tendency to go for the lower buttons and it is a bit bulky and not very portable

The Lightwriter is a fairly sophisticated piece of technology and therefore has greater scope for problems and design flaws. The main problem with the Lightwriter is the cost of £2500.

Some small problems that Aime has experienced are:

- The off button is in the wrong place and it makes it too easy to accidentally turn it off.
- It needs a more suitable voice for Aime – it would cost £1000 to put different voices on the Lightwriter.
- It needs a word predictor that is smarter and can pick up on the person's regular sayings much like word processing software would rather than its own words.
- It should be compatible with a PC and capable of using software for people with learning disabilities.

Lessons learned

Using communication technology requires a skilled facilitator – and a skilled facilitator can help people communicate without technology using something as simple as an alphabet board. All support staff need to be well trained. The people around him are the most important ingredient in making it work and sometimes the technology is not needed.

Michele and Cris need to keep checking that the words are actually coming from Aime and making sure he is in charge of the process. They regularly get Aime's support staff to ask Aime questions that they cannot possibly know the answer to in order to test whether it really is Aime's response.

Positioning, comfort and creating the right environment for thinking are key to making it work. Moving the keyboard if there is a preferential hand side is important.

There is a gap in AT – there is hardware and software based on touch screen or typing but there is nothing that ties together specific sounds with an eye pointing system, touchscreen, body movement recognition, sound vocalisation or a combination that learns from the user.

Software is needed that works more like a personal organiser to repetitively remind the user and helper of tasks and processes that use speech production. This type of software would be more relevant in helping people to live independently.

Investment is needed in training support staff to use facilitative communication so that it becomes integral to the support worker's role alongside personal care and other daily living tasks.

6.7 George Martin

George, a 50+ man, along with a growing number of other folks who receive supports from Hope House Foundation, Virginia USA benefits from technologies that are being developed to assist people with cognitive, age related, or physical challenges become or remain more independent in their day-to-day lives.

George uses a phone with pictures of family, friends, and staff. He can contact them by pressing the picture of the person he wants to call. A simple adaptation of the speed dial feature; a man who for the first time in his life can make a phone call without help from staff. Freedom.

Some folks are using automated medication containers that provide a prompt when it's time to take medications, and allow only the current dose to be accessed, others use automatic door openers, a multitude of communication devices, watches that provide prompts, chairs that lift to assist with standing, etc. There are thousands of items available, and more being developed every day it seems. Many of the products are aimed at the 60s generation, now aging, financially secure, and determined to remain independent and in the community.

A hundred years ago most of us would have needed to learn how to churn butter, make soap, and sew. Fifty years ago we washed dishes by hand, carried cash for all purchases, made popcorn on the stove in a pan, and made coffee in a percolator. Today we rely on automatic dishwashers, microwave ovens, ATM machines and hundreds of other technologies in the course of our day-to-day lives. Technology gives us time to pursue other things.

Should technology replace learning? I say "yes" when it makes sense to trade learning tasks for more time for reaching dreams.

Robin Haverty – Services Director, Hope House Foundation, Virginia, USA contributed to this example which is reproduced in his words.

Chapter 7 Making it Happen

7.1 Conclusion

A draft of this report was presented to a conference of 80 people representing diverse interests from disabled people and carers too providers and commissioners. This conference helped to formulate the conclusions and an action plan.

The conclusions are:

- It is demonstrable that there is a great potential for Assistive Technology to make the lives of people with learning disabilities better and to help gain greater independence.
- We should be positive and upbeat about the potential. The question is 'why has it taken so long to realise the possibilities'. The study provides clues to why progress has been slow and thus also what to focus on to speed up use.
- Access to Assistive Technology should automatically be seen as a 'right', not simply an unusual option.
- There is also the prospect that different parties can share in the benefits of Assistive Technology.
- The focus in the study has been on enhancing life in family and individual living settings but some of the technology available could also enhance life in a more institutional setting.
- There is a lot of useful Assistive Technology already available. Faster, better progress is likely to come from learning from leaders in other fields.

The reservations about AT centre on:

- The possible financial gains carry the risk that money will drive change rather than quality of life.
- Concern about the reliability of the technology and managing risks in the event of failure.
- Danger of being led by the technology rather than careful assessment and undertaking of individual planning.

The study can assist improvement in lives by spreading knowledge and information and contribute to a process of internal change. It would be even better if it could be taken further and become a reference resource or a constantly updated handbook on Assistive Technology for people with a learning disability.

Further work and help would be useful in the areas of:

- Assessment for Assistive Technology.
- Call Centres and how you select and monitor response services for people with a learning disability.
- Staff training in initially assessing and installing Assistive Technology.
- Ethical considerations.

7.2 Action Plan

The conference was asked to consider:

- What action they would like to see from different agencies.
- What would be most helpful in the individual's organisation or to them personally, in developing the use of Assistive Technology.

The specific actions proposed were variously directed at central and local government, manufacturers, housing and care providers. Actions suggested included:

- A national strategy to implement the use of Assistive Technology by people with learning disabilities.
- Supported by ring-fenced funding to act as a catalyst for change.
- Designation of Assistive Technology champions within Local Authorities and other organisations.
- Interactive conferences for people with learning disabilities and more direct involvement of disabled people in developing Assistive Technology.
- Establishment of an 'expert users and carers group' set up by manufacturers to work in partnership with people with learning disabilities.
- Assistive Technology to become an integral part of care assessments carried out by Social Services.
- Action to raise awareness of the role and potential across the board; disabled people, carers, support workers, commissioners…

The things most frequently identified that would help individuals or organisations to develop use of Assistive Technology were:

- Better knowledge of what is available and how to use Assistive Technology in practice. This included:
  - training.
  - information on funding.
  - more examples of Assistive Technology being used by disabled people and the results.
  - visits to example applications.
  - demonstrations.

- A means of keeping abreast with changes and new ideas:
  - database and/or website.
  - handbook regularly updated.

- Development of methods and processes to incorporate Assistive Technology into assessments and care packages.

Advance and the Steering group are not in a position to take these actions, but commend them to all the interested parties. We hope this study will contribute to knowledge and act as a catalyst for giving Assistive Technology closer consideration.

Appendix 1

Preventative Technology Grant

Money has been given to all Social Services Authorities to expand use of telecare. The extracts below from Department of Health publications explain what is available and how the grant can be used. The grant can help provide support to people with learning disabilities, not only older people. More details are available from: www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance

Allocations to Local Authorities in 2006/07 range from £2,000 to £600,000 so in the context of social care as a whole funding is modest; but is intended as a catalyst and to promote telecare.

What is it?

In July 2004, the Government announced its plans to invest £80 million, over two years from April 2006, through the Preventative Technology Grant. The purpose of the grant is to initiate a change in the design and delivery of health, social care and housing services and prevention strategies to enhance and maintain the well-being and independence of individuals.

How should it be used?

Through the grant, the Department expects councils to invest in telecare to help support individuals in the community. This aims to help an additional 160,000 older people to live at home with safety and security and reduce the number of avoidable admissions to residential/nursing care and hospital.

How will it be allocated?

The grant will be allocated to all local authorities in England with social services responsibilities using the Formula Spending Share for Older People Formula. £30 million will be made available in 2006/7 and £50 million in 2007/8. The grant will not be ringfenced. A joint local authority and NHS Circular attaching the formal grant determination will be issued in early 2006.

Whilst the funding will go to local authorities, they are expected to work with partners in housing, health, voluntary and independent sectors and service users and carers. Local authorities and their partners may wish to consider using pooled fund arrangements and joint commissioning under Section 31 of the Health Act 1999.

Using the grant effectively

The grant should be used to increase the numbers of people who are supported to remain independent with telecare. It is expected that most of the beneficiaries will be older people. The current evidence base for the effectiveness of telecare is in its use in supporting older people; however, telecare could be used to support people of all ages, including children.

It is for each local authority and its partners to decide how best to use the grant to modernise local services and incorporate telecare into mainstream health, housing and social care services. The Telecare Implementation Guide provides several examples of existing telecare services. The examples below are intended to illustrate the potential for change.

Implementation issues

Before advantage can be taken of telecare, local authorities will need to ensure that infrastructures are in place to deliver:

- Staff training and development.
- The supply and management of equipment.
- The supply of relevant 24-hour/seven day contact services.
- The supply of 24-hour/seven day care response services.

The grant is intended to pump prime these processes and changes in the delivery of mainstream services. The Telecare Implementation Guide provides detailed guidance on developing and implementing a telecare service. The paragraphs below are intended to highlight key issues that local authorities and their partners will need to address at a local level.

Planning

One of the emerging themes from the forthcoming listening exercise on out of hospital services may be the use of telecare and telehealth systems more generally.

When planning a telecare service local partners will need to consider how the service will fit with longer-term developments for telecare and telehealth systems.

Local partners should develop a local telecare strategy, showing how telecare services contribute to other strategies, frameworks and priorities and how services integrate into existing health, housing and social care pathways. Consideration should be given to the existing infrastructure, such as community alarm services, that can act as a platform for telecare services.

Smaller authorities may wish to consider economies of scale by planning and commissioning services with neighbouring authorities.

Information and advice

People using services, carers and professionals will need access to information and advice on telecare and the services available locally. The Housing Learning and Improvement Network are compiling an online directory of demonstration sites and SMART houses at www.changeagentteam.org.uk.

Procurement

As a general principle, local authorities should follow procurement best practice. They should seek economies of scale in procurement and lower unit costs for equipment and where possible use existing framework agreements and preferred supplier lists e.g. where telecare equipment forms part of the Integrated Community Equipment Service.

There are several options for the supply and ownership of telecare equipment. These include:

- Direct purchase and ownership.
- Leasing.
- Rent/Managed Service.
- Self Purchase.

Ethics

The construction, delivery and removal of a telecare package is subject to the same ethical processes as any other care package.

Some telecare equipment gathers information about the lifestyle and activities of the individual in their own home. Other packages may include passive devices (where the individual does not have to interact for a call to go to a call centre). These packages will require specific ethical considerations around informed consent.

The individual, or their advocate or carer where informed consent is not possible, should understand the implications of the information that may be generated from a telecare package. They will have access to that information and what conclusions may be drawn from the data generated.

Charging

Where, as a result of a community care assessment, telecare equipment is provided by a local authority as an aid for the purposes of assisting with nursing at home or aiding daily living, it should be provided free of charge.
A charge may be made for the service elements (revenue) of telecare. Charging should be in line with local Fairer Charging and Fairer Access to Care Services (FACS) policies.

Where it is part of the local strategy to provide telecare packages to people who are not assessed as requiring them as an aid for the purposes of assisting with nursing at home or aiding daily living, for instance as a preventative service, a charge can be made for the equipment and the service (revenue) elements. In these instances the FACS means test can be used, in the same way as for Supporting People charging assessments.

Where telecare is part of a joint package of health and social care providers will need to agree their respective responsibilities and charge accordingly.

Performance assessment

We will be developing, in partnership with the Commission for Social Care Inspection, a method of identifying the numbers of people benefiting from telecare over the two years of the grant from 2006/7 to 2007/8.

Local authorities and their partners may wish to develop locally agreed targets or outcome measures. Examples could include:

- The numbers of people who benefit from telecare.
- The numbers of carers receiving a telecare service as a result of a carer's assessment.
- The number of people using Direct Payments to buy telecare.
- Telecare being incorporated into local training packages for health and social care workers.
- Satisfaction surveys of users of telecare and their carers.

Appendix 2
Useful Websites

ASTRID Guide www.ASTRIDguide.org

Care Services Improvement Partnership www.csip.org.uk

Centre for Usable Home Technology (CUHTEC), University of York www.cuhtec.org.uk

Disabled Living Centres Council (DLCC) www.dlcc.org.uk

Foundation for Assistive Technology (FAST) www.fastuk.org

Integrating Community Equipment Services (ICES) www.icesdoh.org

National Initiative for Telehealth (NIFTE) Framework of Guidelines
www.cst-sct.org

Ricability www.ricability.org.uk

Social Alarm and Telecare Association (SATA) www.sata-uk.org.uk

Smart Homes databases www.rethinkhousebuilding.org

Supporting People website www.spkweb.org.uk

TATE Project (Through Assistive Technology to Employment) www.tateproject.org.uk

Telemedicine Information Service www.tis.bl.uk – including supplier database, project
listings and organisations

Telecare Alliance – a consultancy specialising in telecare. Produces a newsletter.
www.telecarealliance.co.uk

Telecare Services Association: a membership organisation for telecare and alarms service
providers   www.asap-uk.org

Appendix 3

Assessment pro-forma model

Person's details:

Name ....

Address ....

....

Date of birth ....

Tel number ....

Support worker ....

Tel number ....

Family or advocate details ....

Name ....

Address ....

....

Tel number ....

Reason for assessment request? What do you hope to gain from telecare?

....

....

....

Current situation

Type of accomodation

House   ☐   Bungalow   ☐   Other   ☐

Flat   ☐   Care Home ☐

Is the property shared? Yes ☐   No☐

If yes who with ....

Does the installation have to include other people living in the same property?

Yes ☐   No☐

If 'Yes', how? ....

Access Problems   Position/comments
Doors   Yes ☐   No☐
Shops   Yes ☐   No☐
Interior   Yes ☐   No☐
Keys/locks   Yes ☐   No☐

Other ....

Existing Support

What services does person receive?

Support at home ....

When? ....

Day care ....

When? ....

Education ....

When? ....

Other ....

What are the problems/weaknesses in present support?

Communication

Are there problems with communication that AT might help with or which might prevent some devices being useful or which suggest a particular type of device/prompt?

	Ind.	Problems noted	Unable	Assessors comments e.g. special needs/position
Hearing				
Sight				
Speech				
Telephone				
Pendant alarms				
Pull chords				
Concentration and memory				

If the person has an autism spectrum disorder or complex behaviour are there any particular features to avoid/include e.g. loud noise, reflection, whining?

Behaviour / cognition

Are there any patterns of behaviour relevant to considering AT?

Wanders   Yes ☐   No ☐

Sleep patterns   Yes ☐   No ☐

Anxiety/agitation   Yes ☐   No ☐

Confusion   Yes ☐   No ☐

Other ....

....

....

Lifestyle

In this section we are trying to build up a picture of your lifestyle and daily routine by idetnifying the times and places that you carry out these routines.

Do you generally get up at the same time every day? Yes ☐   No   ☐

Do you generally get dressed straight away? Yes ☐   No   ☐

Which chair do you sit in most of the time? Do you generally go to bed at the same time each night? Yes ☐   No ☐

Do you generally get out of bed at night? Yes ☐   No ☐

If yes, how often? ....What time? ....

Do you have any concerns about your ability to manage at home?

....

....

....

Risk Assessment

This section should be used when there are risks identified and the referrer wishes to use the system to assist in the management of these risks. The outcome of this assessment information will be monitored as part of an audit to consider effectiveness of the system.

Risks	High risk not evident	Low risk	Comment
Unable to follow directions			
Difficulty in decision making			
Unable to express self			
Environmental			
Leaving doors to house open			
Leaving windows open			
Unable to lock door			
Leaves keys behind			
Does not check callers properly			
Function			
Restricted mobility			
Falls when on level			
Falls on stairs			
Epilepsy			
Hearing impairment			
Visual impairment			
Speech impairment			

Risks	High risk not evident	Low risk	Comment
Personal Care			
Bathing risks, scalds, falls			
Handling hot food			
Leaving gas on unlit			
Fire safety risk of CO poisoning			
Unaware when heat is on			
Health affected by not eating			
Medication			
Interpersonal			
Risk of abuse or criminal activity			
Problems of compliance with support services/medication			
Anxious about getting help in an emergency			
Social isolation			
Lack of mental stimulation			
Mental state			
Confusion			
Short term memory loss			
Night time behaviour			
Sleep pattern disturbance			

Please state which devices are required in addition to dispersed alarm		
Please indicate which devices and in which part of the home they need to be installed		
	✓	Where does it need to be installed?
Smoke detector		
Carbon monoxide detector		
Flood detector		
Natural gas detector		
Temperature extremes detector		
Fall detector		
Medication dispenser		
Bed occupancy sensor		
Chair occupancy sensor		
Bogus caller alert		
PIR movement detector		
Pressure mat		
Wandering client alarm		
Enusesis alert		
Door entry system		
Keysafe		
Strobe sounder		
Visual call indicator		
Epilepsy alarm		
Other		
Other		
Other		
Other		

Please state the reasons technology is being requested	
Falls prevention / alert	
Epilepsy alarm	
Prevent residential care admittance	
Accidental prevention	
Supporting carers needs / carer respite?	
Maintaining / promoting independence	
Minimising risk	
Privacy / dignity	
Greater reliability	
Reduce / eliminate sleep-in care	
Reduce / eliminate waking night cover	
Combat social exclusion	
Support...	
Programmable devices information	
Bed occupancy sensor	
What time does the person go to bed?	
How often does the person get up in the night?	
How long does the person spend out of bed?	
What time does the person get up in the morning?	
What should be done in response to an alarm?	
Chair occupancy sensor	
Which chair should the sensor be connected to?	
What time is it occupied?	
How long should it be before an alarm call?	
....when the chair is occupied?	
....when the chair is unoccupied?	
What should be done in reponse to an alarm?	
Motion detector - bathroom	
What hours of the day is the room used?	
How frequently is the room used?	
How long before an alarm when not in use?	
What should be done in reponse to an alarm?	

Please state the reasons the technology is being requested	
Motion detector - kitchen	
What hours of the day is the room used?	
How frequently is the room used?	
How long before an alarm when not in use?	
What should be done in response to an alarm?	
Motion detector - other room (please specify)	
What hours of the day is the room used?	
How frequently is the room used?	
How long before an alarm when not in use?	
What should be done in response to an alarm?	
Wandering person detector	
Which doors need to be monitored?	
Which hours of the day?	
How long after opening should an alarm switch on?	
What should be done in response to an alarm?	

Appendix 4

Acknowledgements