

Introducing AT and Telecare into Learning Disability Support Services in Gwynedd – Benefits and Challenges

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Abstract

The introduction of assistive technologies and telecare in Gwynedd to support individuals with learning disabilities has been achieved through a programme of surveying and auditing need and activities in existing support plans. It had led to the introduction of technology into a number of supported housing situations, initially using the same number of support staff. The safety and efficacy of the systems have been verified enabling the technology to be used for resisting the need for further support in a number of situations, realising efficiency savings of well over £100K in the first year, as well as improving the quality of life of service users and their informal carers. A reduction in the number of night support staff is being planned for several supported housing schemes which will result in major savings in the future. A role for telecarers is proposed where future provision of supported housing is based on clustering schemes around a support hub.

Introduction

People with learning disabilities are being encouraged to improve their Quality of Life by maximising their potential for independence. Assistive technologies, including telecare services, are likely to play a major role in transforming methods of support from those which use staff or informal carers to perform tasks instead of (or on behalf of) service users into those where support workers take on a more supervisory role, only intervening when a problem arises or when encouragement is required.

The population of people with learning disabilities is increasing across Wales, the UK and Europe for two main reasons:

1. Large numbers of children with severe or complex needs are surviving beyond the neonatal period due to improved healthcare facilities and the expertise of medical staff, and
2. A falling rate of mortality amongst people with learning disabilities in the age ranges above 50 years.

Many people with learning disabilities live happily with their parents for many years, but are forced to accept major changes when the second parent dies or is admitted to a residential or nursing home. Others, and especially those who have been integrated into school or college life, may prefer to live on their own in the same way as their peers when they leave their teens. A third group already live in supported housing with other service users, sometimes without any choice in deciding who they might want as housemates. There are yet others, though now small in number, who have yet to be resettled in the community following many years in a hospital environment.

It may be apparent that the items and level of assistive technology required to support each of these four groups could be quite different but the focus should, nevertheless, be on providing a person centred approach to prescription. Only then can each individual benefit from the technology, irrespective of the cost of its provision and the likely impact on support costs.

In this paper, we discuss how AT and telecare are being introduced in the county of Gwynedd and how it is yielding major savings in some cases but none in others. If a suitable AT strategy is in place, and is implemented correctly, then there are likely to be major financial benefits to the local authority while the people with learning disabilities benefit from being able to take more control over their own lives, and achieving major gains in their Quality of Life.

Background

Gwynedd is a largely rural county in North West Wales (see Figure 1). The population is approaching 120,000 of whom nearly 25% are of pensionable age. The Gwynedd Telecare Service was established in 2006 in order to develop support structures for vulnerable people using the Welsh Telecare Capital Grant. The service was expanded and provision extended in 2008 by the appointment of a telecare officer (MJ) within the Learning Disability team, funded by an Independence grant from the Welsh Assembly Government. This new post has enabled deficiencies in current support arrangements for people with learning disabilities to be highlighted, and proposals made for introducing technology into their support plans and lifestyles.



Figure 1: Location of Gwynedd in the North West of Wales

There are over 550 people on the learning disability register in Gwynedd, of whom more than 80% are cared for in the community with the remainder in local authority, private or voluntary accommodation, and less than a dozen in health service accommodation at Bryn y Neuadd Hospital (in neighbouring Conwy County). A resettlement programme is currently in progress that will see these residents moving to small-scale accommodation. There is an ongoing need for shared accommodation within the County, with over 50 adults known to be living with parents or family members aged over 70 years. This will create an increased demand for both support and accommodation over the next few years.

The Supporting People programme in Gwynedd funds a total of 76 units of shared accommodation and 169 units of floating support (including 134 units of independent advocacy support), spread

throughout the County using 7 different providers. The cost of this service provision is nearly two thirds of the Supporting People grant but is likely to come under increasing financial pressure as housing benefit rules are changed.

Reviewing Existing Provision

Before considering changes to the support plan, it was necessary to review existing provision with reference to an assessment of the individual’s needs and the home environment. This process involved both desk research and conversations with the service users, their support workers, their fellow tenants (where appropriate) and their close relatives. There was some suspicion of the motives behind the review, especially by the support workers and by some family members, even though they were all told that the focus was to help the service user to choose to do more things for themselves. The two major concerns were:

1. the safety of the equipment when used by people who are not used to technology, and
2. the number of emergency situations that regularly occur during the night.

It was evident that it would be difficult both to introduce technology and to change the level of night support staff without first addressing these issues and demonstrating that any proposals would provide an answer to all concerns regarding timely responses to emergency situations.

Therefore, a pilot project was undertaken to provide the required proof that assistive technologies and telecare could facilitate a transformation of support for people with learning disabilities in supported housing and residential care schemes. The first phase of the project was to collect reliable data on both the service users and on the interventions made by their support workers. A pro forma was produced and offered to all service providers for completion (see Figure 2).

Gwynedd Social Services		Daily Routine Log	
Address:			
Date:			
Staff on duty (with times):			

Service User 1			
Time that they got up:		Time that they went to bed:	
Time that they went out (without staff):		Time that they returned:	
Time that they went out (with staff):		Time that they returned:	

Service User 2			
Time that they got up:		Time that they went to bed:	
Time that they went out (without staff):		Time that they returned:	
Time that they went out (with staff):		Time that they returned:	

Service User 3			
Time that they got up:		Time that they went to bed:	
Time that they went out (without staff):		Time that they returned:	
Time that they went out (with staff):		Time that they returned:	

Service User 4			
Time that they got up:		Time that they went to bed:	
Time that they went out (without staff):		Time that they returned:	
Time that they went out (with staff):		Time that they returned:	

Figure 2: Pro forma for Service User Lifestyle Information

A second form (see Figure 3) was produced to enable staff interventions at night to be audited. This was completed by staff over a 3 month period. During this period, a range of appropriate telecare devices was installed into two properties where an assessment had shown the potential for

improving the level of independence during the night through a reduction in the number of sleep-in carers. The technology included the **WeSpot** non-contacting and wireless bed occupancy sensor which was programmed to provide an alarm if the service user left their bed during the night but failed to return within a programmed period of time. This uses sophisticated shape analysis to detect when a person has left the bed. Although a conventional bed occupancy sensor using a sensor pad under the mattress could have been employed, such an approach was considered to be likely to lead to interference by service users at some stage. In practice, the WeSpot sensors were mounted on the wall above the pillow and gave excellent and reliable results. The service users ignored them and they became largely invisible to them and to members of staff within a couple of weeks. Alarms generated by the telecare equipment were directed to portable alarm receivers that were either carried by members of the support team or, at night, located in the room occupied by sleep-in staff members.

Gwynedd Social Services Supported Housing Incident Log									
Address:									
Date:									
Staff names and hours:									
Reportable Incidents									
Time	How Incident Detected (e.g. sensor)	Type of incident (e.g. shouting)	Intervention (e.g. words of comfort)	Outcome (e.g. service user returned to bed)	Incident closure time	Person(s) responding	Time from Incident to Intervention	Location of incident	Recommendations

Figure 3: Incident Log Used to Log Incidents During the Night in Supported Housing.

At the end of three months, staff and other stakeholders had become convinced that the telecare equipment was safe and that serious incidents during the night were infrequent and likely to be detected more quickly using the telecare system than relying on sleeping staff waking up. This provided the evidence necessary to look at reducing sleep-in night staff provision. In general, reducing 2 support staff to 1 was relatively simple at this stage, providing that the evacuation procedures had been revisited and an individual plan produced for each service user.

Accelerated Auditing of Support Staff Activities

For future audits of activity, it will be possible to use Lifestyle Monitoring systems to demonstrate the ability of service users to get up on their own during the night with the help of sleep-in support workers. The approach involves using movement detectors in each of the rooms of a supported home including the bedrooms of the service users and their support workers. This yields an hour by hour display of movements on a continuous basis. It may be viewed as a 24 hour display or, it may be used to focus on time slot during the night when movement would not have been expected. Such a system can be used for a period of a few weeks to show which of the service users is active during the night, and where additional risk management procedures may need to be put into place.

A summary of telecare packages deployed to date is provided below, some of which yield significant efficiency savings, whilst others improve the quality of life of individuals and their carers.

Examples of Efficiency Savings

With the benefit of having the evidence of safety to transform the care packages, all new referrals to the LD team are considered on the basis of using telecare and AT before the need for support staff. This has meant a number of packages that are smaller and more focused on the actual needs of service users. In particular, attempts to provide more than one sleep-in support worker have generally been resisted and an arrangement introduced with telecare ensuring a more rapid and appropriate response in the event of an emergency.

~~Table 1 describes the situation for 6 service users for whom equipment and a telecare service have been introduced as an alternative to the additional support workers and hours requested by the care agencies. In the past, the requests of the agencies would have led to extra provision on the grounds of maintaining the safety and well-being of the service users. The total efficiency savings for these six cases over a 12 month period are over £113,000 for a capital outlay of less than £5000 including installation plus annual monitoring fees of under £200. The programme of auditing of night and evening provision described above will quickly lead to more significant savings as existing provision is reduced and where telecare and AT equipment replaces the often intrusive role of support staff in managing the defined risks to safety. It is anticipated that annual savings in excess of £500,000 per annum can be achieved through a more progressive approach in which existing long term arrangements (including the use of more than one member of staff at night) may be replaced by telecarers. A programme is currently underway to reduce sleep-in staff provision from two to one where there telecare can manage the identified risks. Further changes are being considered for cases where properties with support are clustered geographically.~~

Table 1: Efficiency Savings Due to the Use of AT and Telecare in a Care Package.

Case	Care package before Telecare	Telecare equipment and cost	Care package with Telecare	Efficiency savings
Adult with challenging behaviour moving into supported living	Currently receives 2:1 day support but providers seeking 2 x sleep-in staff at a total cost of £100 per night (pn).	Bed occupancy, property exits, flood detectors, pagers. Cost: £1,252	One sleep in provision at a cost of £50 pn.	Annual saving of £18,200 .
Client returning home following surgery after a night-time fall at home	Shares 24 hour support with 2 other tenants. Providers want waking staff at £143.52 pn	Bed absence sensor and pager system installed Cost : £426	1 sleep-in support staff at £245 per week.	£6,077 (over 2 months)
Service user with a history of falling.	Shares 24 hour support with 2 other tenants. Providers seek waking nights at £111 per night.	Bed and chair occupancy sensors and a pager system Equipment: £596	Continue 1 sleep-in at £68.86 pn	£6,271 (over 3 months)
Insulin dependent diabetic living with family but in his own part of the property.	10 hours support at £139.12 per week. Extra hour a day sought for carer's breaks at regular intervals. Extra cost: £122 per week.	Telecare package with fall detector and movement sensor. Equipment: £638 + £56.65 monitoring fee.	Maintain current care package	Annual saving of £6,344

Case	Care package before Telecare	Telecare equipment and cost	Care package with Telecare	Efficiency savings
2 adults in shared tenancy. Issues with smoking, cooking & going out at night and admitting unsavoury people	One staff member providing sleep in provision at the cost of £35 per night.	Telecare package with smoke alarms, extreme temperature sensors and gas detector. Cost: £808 + £56.65 p.a. monitoring fee.	Remove sleep in provision.	Annual saving of £12,718
Vulnerable adult with history of epilepsy living in his own flat	Receives 1:1 at home at night but alone for 4 hours a day. Providers want 20 more hours per week at £13.76 per hour.	Basic Telecare package with fall detector. Equipment: £589 + £56.65 p.a. monitoring fee	Care and support package are unchanged	Annual saving of £14,300.

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Using Technology to Improve Care Provision and Quality of Life

The role of AT and telecare is not restricted to making efficiency gains. Rather, it offers improved independence and Quality of Life for many of the existing service users who currently have to rely on a support worker to help perform mundane domestic tasks, and also to those who might otherwise have to endure intrusive interventions by staff in order to manage risk. The examples shown in Table 2 also show how technology can also benefit carers, especially where family members must endure the stress of providing 24/7 support. The majority of cases currently involve people who occasionally suffer epileptic seizures. Current sensor technologies using electro-active sheets placed under the mattress, or movement detectors placed under the legs of the bed, are now so sophisticated that they have completely replaced baby alarm technologies that relied on a carer hearing the sounds associated with a seizure. In the same way, incidents of enuresis, which are also common in this user group, can be detected wirelessly and used to provide an alert either to the individual themselves or to carers elsewhere in the property.

The examples shown in Table 2 cost a total of less than £4,000 with on-going monitoring costs of slightly over £100 per annum. However, they are dominated by linked telecare systems based on alarm technologies. These are ideal for improving risk management and for relieving anxiety but many of the Quality of Life gains result from the introduction of standalone devices including different types of reminder, and technologies for location support. Their introduction has been more gradual and has required specific technical support from third parties as they are not part of the inventory of telecare sold by the major telecare vendors. In order to embed an extended use of the electronic devices within care packages, the training regime has been developed to include a resource guide that staff can use for reference and for considering issues of interoperability. This needed to be constantly updated as new devices appeared, so an online version was proposed. This has now been implemented as the Telecare Equipment Prescription Guide (Telecare EPG) from local telecare specialists, T-Cubed, who have licensed access to all Welsh Local Authorities. It provides informed opinion and advice and therefore does not suffer from criticisms of being an on-line catalogue as others have produced. The Telecare EPG has been particularly successful in helping staff to select appropriate devices to manage problems of smoking, and of locating service users when outside the property.

Table 2: Examples of Technology Used to Improve Lives of Service Users and their Carers

Case	Care package before Telecare	Telecare equipment and cost	Role of Telecare & AT
Adult with epilepsy living in LD residential home.	24 hour staff provide support to all the residents	Bed epilepsy sensor call staff pagers. Standalone equipment cost: £619	Safeguarding and risk control. Giving individual more dignity.
Adult with chronic lung disease living with his father.	Father is main carer and is anxious about coping with problems during the night	Alarm pendants etc. programmed to call father's pager. Equipment cost : £339	Father's confidence improved
Adult with epilepsy living independently with young daughter in the community.	The individual receives professional support in her home.	Telecare package plus fall detector, property exit sensors, bed epilepsy and occupancy alarms, medication and other reminders. Equipment: £1,661 + £56.65 monitoring p.a.	Safeguarding of mother and daughter. Maintain care package.
Adult with epilepsy living with his elderly parents. Recent surgery on his knee.	Receives professional support in his home. Parents are his main carers.	Basic Telecare package Equipment: £513 + £56.65 monitoring	Maintains care package and supports the arrangements.
Adult with epilepsy and challenging behaviour sharing supported accommodation with one other tenant.	One sleep in staff member at £35 per night.	Bed epilepsy sensor to call staff pager. Standalone equipment: £619	Safeguarding. Risk control. Maintain current care package.

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Discussions and Conclusions

The programme of introducing assistive technology and telecare into the homes of people with learning disabilities is already showing great potential for making efficiency savings whilst also improving the lives of service users and their carers through less intrusive risk management strategies. It is evident that people with learning disabilities have been over-protected in the past, often through the use of excessive numbers of support staff during the day and especially at night. This is a situation that is seen right across the UK. By auditing the actual needs of service users, and the events that occur during the night, it has been possible to take the first step in reducing the dependence of service users on members of staff. Service users are therefore empowered to perform more domiciliary tasks for themselves, including food preparation and laundry, supervised initially by support staff. Ultimately, this supervision could be performed by intelligent devices which can either notify the user if the actions are unsafe, or they could take control of the situation by switching off electricity or water supplies. This may create the “smart home” scenario that many people have predicted for a number of years.

The efficiency savings projected for the first year of the AT and telecare programme are modest, but with dozens more supported housing schemes to be surveyed and the actual needs of the tenants considered, much larger savings are likely in the future. However, to realise these benefits it may be necessary to revisit both the selection of properties being used to house people with learning disabilities, and the criteria employed to find the right mix of tenants. Many people with learning disabilities also have sensory handicaps as well as having to overcome physical problems. Consequently, some family properties which have accommodation on 3 or 4 floors are not ideal. In the same way, maintaining high staffing levels for the benefit of only one of a number of tenants disguises the size of the support package for that individual, whilst denying the other tenants the opportunity to do more for themselves. However, it must be recognised that it may be inappropriate to move someone from a home that they have lived in for a number of years on the grounds that their needs are not matched to those of the people that they share their tenancy with.

It follows that the greatest benefits for AT and telecare might be achieved in the future where new tenancies are created with technology providing the primary means of support. This may extend to the use of more generic telecarer response services that enable all forms of sleep-in and wakeful night support to be removed. The response time of a sleeping carer can be several minutes and this may not be significantly faster than a dedicated team of wakeful carers who are available to respond at a moment's notice. Providing that the telecarers are situated within 5 or 10 minutes of where emergency support is needed, then it is unlikely that the arrangement cannot satisfy all the safety concerns of relatives and friends. This may be achievable in urban areas but may be difficult in more rural situations where more innovative approaches may be required.

The next stage in the Gwynedd LD strategy is to offer more support to informal carers who are currently looking after people in their own homes. There are many standalone devices that can provide them with improved ways of maintaining support in a less intrusive manner. Such devices are portable and can be used in future housing provision. Many will rely on new digital technologies that can be delivered through the computer, the TV or through smart phones. These will be investigated further during the next 12 months.