CUMBRIA RURAL HEALTH FORUM

Use of Digital Technologies in Assisted Living for people with Learning Disabilities in Cumbria

Outline proposals from a workshop held in December 2015

NORTH WEST COAST ACADEMIC HEALTH SCIENCE NETWORK

ACADEMIC HEALTH SCIENCE NETWORK NORTH EAST AND NORTH CUMBRIA

1. Introduction

The Cumbria Rural Health Forum[1] has developed the Cumbria Strategy for Digital Technologies in Health and Social Care[2] and is conducting a number of digital implementation workshops, between October 2015 and March 2016, with the aim of proposing specific ways in which digital technologies should be implemented within a pathway, place or around a particular group of individuals. As with all our activities, workshops bring together professionals from the public, private and third sectors, linking to suitable technology providers as needed. The scope for our work on digital technologies includes telemedicine, telehealth, telecare and assistive technologies, e-health products and services that are commercial available[3] .

This third digital implementation workshop focused on Assisted Living for people with Learning Disabilities (LD). The objectives described and reported here are:

- Share an understanding of what is possible, what technologies have been used in social care of people with learning disabilities and other groups, in Cumbria and elsewhere, and how successful they have been found to be;
- Brainstorm and propose opportunities for implementing digital technologies with the identified group in Cumbria;
- Develop and agree an action plan for the group, to influence change in Cumbria and elsewhere.

2. Use of digital technologies in social care: how has it been used?

Telecare and assistive technologies (AT) are widely used in social care across Cumbria, across all client groups.

Telecare services are available through Cumbria County Council or private providers. Telecare equipment links monitoring sensors to a 24/7 call centre from where a response can be arranged if needed. It is possible to monitor a range of risks and hazards in the home, such as:

- Falls
- Epilepsy
- Chair, bed sensors
- Movement/inactivity
- Door opening
- Bogus caller
- Temperature extremes
- Smoke
- Carbon monoxide
- Natural gas
- flood

These can be used to manage risks associated with independent living:

[1] See www.ruralhealthlink.co.uk
[2] See http://www.ruralhealthlink.co.uk/about-us/cumbria-strategy-for-digital-technologies-in-health-and-social-care/
[3] See http://www.ruralhealthlink.co.uk/assets/uploads/reports/Briefing_paper_Digital_technologies.pdf for a fuller discussion

- Getting lost – linked to GPS if someone wishes to leave the house
- Harassment/hate crime
- Unwelcome visitors
- Cooking safely – through heat and smoke detectors
- Alerting help if seizures occur

Telecare provides a base unit which is plugged into a customer's landline and is configured to work with a personalised selection of sensors for use around the home. The base unit can also provide voice prompts on a timed basis (to get ready for activities or to prompt to take medication) or when a sensor is triggered (to give a warning when opening the front door).

Cumbria County Council (CCC) uses a product called **'Just Checking'**[4] to assess needs of clients. Just Checking units are placed with an individual for 4-6 weeks to understand their daily routine and find out what the problems are (for example, if someone habitually leaves the house or gets up frequently in the night). There are 69 units available, which can be requested through CCC social work or other staff. A project is underway to review support provided by a number of LD residential homes to explore if technologies could be used for greater efficiencies (change residential care to supported living, convert waking night to sleeping night) and to improve quality of care and quality of life (foster greater independence, personalised support).

Monitoring can be extended outside the home using **safe walking** products. There is a current trial of 20 Everon Vega GPS watches supplied by Everon[5]. They can be configured with a safe zone and then alert responders if the wearer goes outside this zone, or can be used by the wearer to call for help by pressing a button. If an alert is given, the responder will automatically have details of the wearer's location to provide assistance promptly.

It is also possible to use **stand alone assistive technology**, where there is no remote monitoring via a call centre and hence a lower cost. A trial of a limited range of stand alone AT is under way. This trial provides a simple pager which alerts a carer to a risk. Bed, chair, door and motion sensors are available[6].

Many other devices can be assessed for on an individual basis, depending on need. These include:

Environmental control systems - simple remote control of TV, lights, alarms, intercoms, door, window and curtain openers, phones, pagers.
Vision impairment equipment such as magnifiers and devices placed on drinking cups to indicate the level of hot liquid.
Hearing impairment equipment such as vibrating personal pagers linked to a door bell and vibrating flashing alarm clocks.

These kinds of equipment can provided through the Council, by specialists in the field who conduct an assessment and advise on appropriate technology.

There are many other solutions available that could offer opportunities in Cumbria.

[4] See website www.justchecking.co.uk
[5] See website www.everon.fi
[6] For a selection of devices, see http://www.easylinkuk.co.uk/page144.html or https://www.nrshealthcare.co.uk/

There is a wide range of stand alone AT equipment available commercially including memo minders, medication dispensers, simplified phones, simplified remote controls and simplified microwaves.

Readily available computer devices (laptops, phones, tablets) can be configured or monitored to provide appropriate support. These day-to-day items have huge assisted living potential. Carephones (specialised mobile phones) are available with quick call and panic buttons. They can also provide GPS tracking and falls detection. Computers and apps can provide a range of AT from online shopping, social contact, prompting etc. Tablets and laptops designed with different keyboards or simpler button layouts are available.

Although current telecare solutions are designed to support people living in their own homes, stand alone devices are available for use in supported living, extra care and residential care settings. One example is the Care Assist[7] – a stand alone pager used in establishments configured for multiple customers and sensors. There is an issue around who funds and responds to these. Extra care schemes are being encouraged to install flexible alarms systems which can provided additional telecare sensors when needed by customers.

There are a number of demonstrator projects for 'smart homes' that are built with installed sensors and equipment to support residents. None have been identified specifically for people with learning disabilities, but a good resource is the Stirling University virtual care home for people with dementia.

3. Issues with implementation of telecare and assistive technologies with people with learning disabilities in Cumbria

Many of the services provided using digital technology in telecare and assistive technologies are aimed at the frail elderly, those with dementia or physical disabilities. Although analysis of usage in Cumbria shows that use in LD is similar to those of other client groups, it was noted that there are relatively few services aimed specifically at those with learning disabilities. Delegates identified a number of specific issues that need to be considered in this context, as distinct to other user group contexts.

The Joint Health and Social Care Learning Disabilities Self-Assessment Framework for 2014 reports that there are 2460 people with learning disabilities in Cumbria. However, learning disabilities are a continuum and many people with mild LD live independently or with minimal family support. Cumbria County Council funds support for 1342 people, most of them under 65. Of these the majority have community based support, with 226 in care homes. The organisations providing care to people with LD include private providers, voluntary groups and statutory health and social care providers (Cumbria Partnership NHS Foundation Trust, Cumbria County Council). Support workers and volunteers often provide hands-on care with limited training and development opportunities. Access to telecare and assistive technology is through occupational therapists, social workers and others employed by the statutory providers. Commissioning of services from private and third sector providers is by Cumbria County Council or Cumbria Clinical Commissioning Group. Families may also purchase products or services (such as phones, laptops, apps, low cost alarms and sensors) directly if they choose and are able to.

The fragmented nature of provision means that providers are unclear what assistive technology can offer and how to take advantage of it. Delegates felt that there is a lack of awareness amongst professional case workers, with variable levels of understanding. This means that professionals do not lead and advise on promotion of AT. It is not built into process and considered by carers.

[7] See website http://www.tunstall.co.uk/solutions/care-assist

As with many digital technologies, there is an assumed emphasis on efficiency and an expectation that introduction is driven by cost savings. Clients and families may resist AT for this reason. Furthermore, in this case evidence of actually achieving efficiency (reduction of people/workers) is limited.

A major issue raised was around response services. Delegates from provider organisations raised concerns around the expectations on providers. If they are providing 24/7 cover through monitoring, then they are judged to be accountable by CQC, even if they are only commissioned to do 20 hours per week. A response service may not be quick enough in a rural area where physical response could be some travel time away, compared to having a staff member on site. In some cases (eg. epilepsy), the individual requires a response within minutes. With people with LD, there can be issues around who can respond – will they be known to the person or a stranger? The needs of this client group can be very hard to describe to someone who is unfamiliar with them. Many clients would not be able to, or would be distressed by having to, deal with a call centre or a machine. The Council does not commission a standardised response service because they are very difficult and expensive to provide and as set out above won't meet everyone's needs. In practice response arrangements need to reflect the needs of the individual. There can be a tendency to be (overly) protective and seek to provide immediate response, but this needs to be tailored to individual or client group needs.

Some ethical issues were raised amongst delegates, which would need to be resolved. Although AT can lead to increase in independence, it also leads to increased risks. Is safety more important than independence? The likelihood of harm may be low, but the consequences are severe. Privacy may be affected. There need to be clear processes for clients or families to refuse. The Council operates a risk taking for positive outcomes policy which expects risks to be identified and managed. Further work is needed to support LD providers, family carers and relatives to agree appropriate processes for each individual.

There was a concern that there could be capacity issues if clients are given access to 24/7 services. They could use the opportunity to ask more of providers. Again, there is work to be done on agreeing processes and levels of support, with carers, providers and the individuals.

4. Exploring options for using assistive technologies and telecare with people with learning disabilities

Delegates worked in groups to identify new ideas that could be developed for this client group. The discussion was structured around 4 themes.

4.1. Theme 1: Access to information and training

Idea	Benefits	Barriers
A web based one-stop-shop for information on what is available, how to access it, maintenance issues, support and response considerations. Include case studies on benefits and 'how-to' guides. Need to understand ethics issues too.	Technology will be used more effectively if appropriate	Cost. Who should host it (CCC?)? Leadership.
Involve suppliers to promote their equipment and services.		

Create a social enterprise to provide equipment – possibly linked to a provider organisation		Coping with fluctuating demand
Virtual provider forum to share information		
Personal stories from users (and carers) – on Patient Memoirs site?		
Shared multi-agency framework for skills training		
Peer support for parents/carers or service users – access to website and online forums, video links, training, sharing stories		

4.2. Keeping people safe at night

Idea	Benefits	Barriers
Select clients and homes where telecare and night time monitoring could be effective	Reducing number of staff on night duties (hard to recruit staff – can use them better during the day)	People with LD may disable equipment or be unable to interact with service. Risks if technology does not work. Consequences for providers who may be held responsible by CQC.

4.3. Young people

Younger clients may be more receptive to technology and may have used it at school. There is also an opportunity when someone is entering residential care to implement a different kind of service.

Idea	Benefits	Barriers
Use software and apps designed for LD users	Promotes independence. Efficiency gains (cost savings)	Users could damage equipment. Ethical issues for cameras. Could increase vulnerability. Funding for Wi-Fi.
Use Raspberry Pi for low cost internet access		
Find out what is being taught in schools and build on that		
Modify assessment – not only to look at daily living but also to assess skills and preferences for technology		

4.4. Smart homes

Idea	Benefits	Barriers
Use smart homes for assessment/observation and for people to look at assistive technology. Can we get a demonstrator in Cumbria?	See who is suitable for what technologies	Cost

Develop capability in turning existing homes into smart homes (not just new build)	No need to move house	

5. Action plan and recommendations from the group: what should be done in Cumbria?

A number of opportunities to influence change and lever funding were outlined.

- Cumbria Clinical Commissioning Group (CCG) is leading the development of a Local Digital Roadmap for Cumbria, as required by NHS England (see https://www.england.nhs.uk/digitaltechnology/info-revolution/digital-roadmaps/). Funding priorities for Cumbria will be linked to this and the group's recommendation will be fed back to the CCG.

- Cumbria County Council is undertaking a procurement of a new Cumbria telecare and assistive technology service to start 1 October 2016. The new service will extend the range of equipment available to include stand alone AT and safe walking devices alongside the more traditional monitored Telecare. The service will also offer an Information and Advice Service which will respond to requests for information and advice and promote use of Telecare and AT widely.

- The University of Cumbria has launched new Continuing Professional Development (CPD) course modules in Digital Health and Social Care (see www.cumbria.ac.uk/digitalhealth) . Funding is available to support individuals based in South Cumbria at present. Each student will do a work-based project, which could be proposed by this group and offered as suggestions.

- The group could decide to implement new technologies directly, subject to a positive business case.

Proposed actions are:

- The Cumbria Support Directory (hosted by Cumbria County Council) could be enhanced to provide online information about what AT is available and supported locally, how to access, what are the costs.
- Discussions should be held with CLIC on training needs – how to use technology.
- Steps should be taken to ensure care providers have appropriate technology to undertake support duties effectively (eg. access to mobile devices for support staff) – this could be a condition of tenders.
- Approach Patient Memoirs to discuss including some users of AT.
- Ensure the benefits and outcomes of the Just Checking project are evaluated.
- Although, a mechanism exists for providers/social workers/other professionals to consider use of AT for new clients and at progression, it is not implemented consistently. Guidance and training could address this issue.
- Hold local events to promote options and equipment to education people, families, providers, practitioners, which could be part of the new contracted information and advice service.

4. Authors and affiliations

The workshop was led and co-ordinated by Alison Marshall and Elaine Bidmead, University of Cumbria. It was hosted by Glenmore Trust, Penrith. This report is produced jointly by all the attendees of the workshop, listed in alphabetical order:

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