



Transcript:

Narrator: A greater need for personalised care, the fact that people are living longer and scarcer economic resources are all pointing to a far wider use of technologies to assist people who need care.

Keren Down: There's no way that telecare isn't going to feature in the future. We don't have anywhere else to go, it's the only game in town. We have no more people. We have no more money and we have no more carers. In fact, we've got diminishing amounts of all of those. One, this was very clear. We've got to look at both technology and self-care as a way of managing more fairly limited resources and limited care of time.

Narrator: This programme takes a look at the ethics surrounding telecare. It touches on some of the issues highlighted in the SCIE report on telecare ethics, which was based on work carried out by the Welsh Centre for Learning Disabilities. SCIE's report examines the ethical issues that practitioners and others should think about when supporting people to use telecare services.

Dr Steven Beyer: For the last six months we've been producing an ethical code of practice for the Social Care Institute for Excellence which provides some framework for guidance for professionals who are considering introducing assistive technology and telecare to people primarily with cognitive disabilities. Assistive technology and telecare can be hugely positive in people's lives. It can help people stay at home longer. It can help to maintain and also increase their independence and autonomy. It can change the relationship that they've got with their carers, their families but with that also comes some threats, threats to privacy, threats to autonomy. Basically, we want to be sure that as well as looking at the positives, that professionals also consider the detrimental aspects that may be there unless they plan around it. So,

that's why we're producing a code that draws out some of the practical implications of that.

Narrator: One of the biggest ethical considerations is a simple one. Can the use of technology make people's lives better? .

Keren Down: There is an enormous potential to bring in some of these new technologies and that's going to happen, we're going to have interoperable systems, we're going to much more complex system in people's homes. The one thing about these technologies is you can't just bolt them on. They actually have the power to completely transform how you deliver services.

Narrator: Alan has a learning disability and lives in a residential home. He uses a specially adapted mobile phone and an electronic pendant linked up to a support unit to give him independence.

Alan: I've got a pendant. If I press it I will ... now somebody's got to come. I'll feel good and it will know I'm going to be saved.

Deanne Aris: By Alan having the technology of the phone and the pendant it hasn't altered the level of support we give Alan, it just gives him the freedom of being able to stay in his room without staff interrupting him. He does live with five other people and we are busy with those over five. We can't keep going in and checking him and he wouldn't want to. It's his room and I wouldn't want somebody coming in every fifteen minutes to check if I was alright. So he can actually do what he wants in his room, get on with and we know peace of mind that he's sat watching tele or tidying his room, so we know he's safe.

Narrator: But the potential for staff to perhaps spend less time with users of the technologies highlights another ethical consideration. Could telecare lead to an increase in social isolation?

Dr Steven Beyer: It's important to recognise that assistive technology and telecare cannot monitor everything in people's lives. It's very important that care staff, families do have a role, that technology can provide some information, it can't provide all of that, so there has to be, for some people, a

continuing emphasis on social care, on human contact if they're going to be provided for in the most effective way.

Steve Barnard: In using technology people are very frightened that suddenly there'll be social isolation and my response to that is are you actually with this person because they have epilepsy and that's the reason for the social contact is because of their particular need. The social contact should be about friendship, about people you get on with, you enjoy, not about which disability you have, so the more needs you have the more friends you have, so I think that our role, as professional carers, is to try and help people develop their own social networks.

Narrator: Pauline lives in supported accommodation with Hazel. Both women have a learning disability. With the help of telecare they don't need full-time carers.

Pauline: I've got a buzzer upstairs in my room but I don't use it unless if I really have to. If the house gets hot, that's a heating alarm and that one is a smoke alarm. If the hob get too hot that goes off. I'll be safe if I have some support from the staff but if the staff are not here I can go for on call staff from Lavender and they go onto the centre. I like to be independent, I'd rather do it myself than rather having people do it for me because if other people do it for me it just like that I'm being a child.

Dr Steven Beyer: Of course it could be seen as much cheaper to bulk purchase a whole of set of kit and put it into people's homes, but the real danger of that has to be recognised but in the long-term, for many people, you will overplay the safety aspect at the disadvantage of independence and autonomy and that will eventually lead you to great costs in the long run and also to lower our wellbeing and quality of life.

[Sitting in garden]

Hazel: What's that?

Susana Veriato: You have a try Pauline? That's got a distinctive smell. Rub it on your fingers Pauline and will leave the smell.

Susana Veriato: Pauline has come from a residential house into supported living and she's lived here I believe it's round about three years. We would never have thought that Pauline was ready to move into supported living and with the assistive technology it enables these guys to live more independently because of the prompts and the security and everything else that goes with it.

Keren Down: When you look at the code of practice which is being put together a lot of it is about putting an ethical approach to delivering telecare services in the context of good practice. Good practice is delivered by the workforce. If we don't have a trained workforce how can we expect to have good ethical practice. If we don't have training and education how do you promulgate, how do you cascade down ethical practice and so on. So it's really important that we improve the whole training and education and workforce development practice in order to achieve ethical good practice.

Narrator: The code highlights the rights of the individual. Users of the technologies or their carers must consent to its use and may reject it.

Dr Kevin Doughty: My mother died twenty five years ago. So my father is isolated. He lives on his own and because he's now eighty eight of course he's at risk of an awful lot of problems including falls, he's diabetic. He's trialled many, many devices over the years but he keeps none of them and he always says, "that's good but give it to someone who needs it." But at some stage he will suffer a fall and he will recognise that it is for his own good. Until that day comes he is right to reject it. I think what we need is to have people understand what's available so when the time does come it'll be readily accessible for them. Then they will accept it, believe me.

Narrator: Rita and Derek have lived on their own since their marriage fifty six years ago but recently Rita has developed Parkinson's disease and Derek has Alzheimer's. To enable them to live independently the local authority has commissioned a telecare service, which includes a door sensor.

[sitting in Rita's home]

- Avril Pritchard: If it was up to you would you choose to keep it in for the moment?
- Rita: Yes. We would keep it although at the moment we don't really need it but knowing that it's there and we can have it switched off at any time it will give us great comfort.
- Avril Pritchard: Taking into consideration Derek's capacity to enable him to make decision I think Rita's input was vital and imperative to the route that was taken in this case. Everyone who had an input, their input was important to the end result.
- Dr Steven Beyer: A person's ability to make a knowledgeable consent will be dependent on the complexity or the simplicity of information given. Now, certainly we've found with people with learning disabilities that if you approach that creatively by providing demonstration, providing DVD's that show how equipment can be used. It can then show them in a way that enables them to make a knowledgeable decision. What we want to do is extend that principle to others.
- Narrator: The cost and availability of telecare is another area the code discusses raising the idea of justice. The debate is around the notion that those whose lives will be improved by the technologies should have a right to access it.
- Karen Down: I have some concerns about the fact that there's been some research recently that people who have had the opportunity to top up on prescriptions for equipment, for example, or who are going out with individual budgets just aren't aware that this equipment exists so they're not able to exercise choice. Unless we actually tackle workforce development and get practitioners championing it, raising it to people's attention so they know it's out there, until we start getting that public awareness thing happening people aren't going to go and vote for something they don't know exists.
- Steve Barnard: The funding is probably the biggest issue and you've got two aspects of the funding. One is the capital, how much do the gizmos cost and the other one is how do you maintain it. Now, there are no formal funding

streams so you build it into your current way that you cost your services.

Narrator: In the past 80 million pounds has been provided by Government to local authorities to improve the uptake of telecare. Local authorities now fund it in the same way that they fund traditional social care support and one pilot scheme seems to show that using telecare services can lead to savings, albeit to other sectors such as health.

Andrew Lomax: We did a small pilot run where we had permission from thirty six customers to pass their details to the PCT.

[Sitting in lounge]

Andrew Lomax: And we can get someone to go through, come and look at what you needs are and look at putting further equipment in if you need that. That can be anything from grab rails, it could be more telecare equipment. There's a whole host of things we've got out there but we'd really try to design that around you.

Andrew Lomax: The result that we got back through was that there'd been a forth three percent drop in accident and emergency attendances and a sixty two percent drop in emergency admissions and with the emergency admissions low that was a cost saving of like £27,000. So ... and that was on a very, very small target group as well.

Rita: It's important, all this, so we can stay together and not have to be split into homes. It's really important.

[End of Recording]