Executive Summary

Keeping in Touch with Technology?

Using telecare and assistive technology to support older people with dual sensory impairment

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Executive Summary

Recommendations Arising From The Study

Recommendations for SENSE,
working with other charities, including: Action on Hearing Loss; Age UK;
Blind Veterans; Grand Charity; RNIB; and the Thomas Pocklington Trust

1. **Develop a new, high-profile campaign for joined-up support and a common standard in supplying telecare and technology to older people with DSI,** to achieve the following outcomes:

- New accessible *information on how technology can help older people with DSI: outside the home environment; inside the home; and in communications and social interactions.*

- New simple and accessible *'top tips' guidance for families and carers* supporting an older person with DSI, available in different formats.

- New *guidance for equipment installers, care workers and others who work with older people with DSI* on common issues / key points to consider when providing a service to them.

In these outputs, use examples of older people with DSI who have used technology effectively or with transformative results as inspirational, positive and realistic case studies.

2. **Enhance and develop existing SENSE support for older people with DSI,** by:

- Working with SURGE and RICA to *establish an advisory panel of older people with DSI to work with professionals,* collaborating with them and other agencies to establish a forum and competition for new person-centred technology support.

- Add *new functionality to Sense's technology webpages* to enable older people with DSI who use technology to share what works for them and how they have overcome difficulties.

- Adapt and extend Sense's Usher Peer Mentor Scheme *to offer 'buddy' or 'best friend' support to older people with DSI,* providing them with ongoing personalised guidance in using technology and addressing problems.

Recommendation for ADASS and the Local Government Association, *working with local authorities and other providers in health and social care*

3. **Work with local authorities and their partners to extend telecare support to older people with DSI**
   - *Offer all older people with DSI an individually tailored telecare package* with other relevant technologies.
   - Develop *a specialist training programme for professionals in contact with older people with DSI,* as preparation for the projected significant growth in their numbers, recognising the complexity of their needs and educating them in how best to address these.
   - *Urgently address the limited range of technology offered by some local authorities,* ensuring improvements focus on all areas of life important to older people with DSI, not just risk and safety.

Recommendation for the Department of Health, *working with the Telecare Services Association*

4. **Set up a single, accessible and independent technology advisory service for older people**
   - Ensure this offers *bespoke and targeted support for those with DSI,* with troubleshooting support and accessible re-assessment as standard features.
   - Develop a *publication for TSA members covering common areas of difficulty older people with DSI have in using technology,* with advice on how to address these in product design, arrangements for service provision, and post-installation support.

Recommendation for Innovate UK, *working with innovators and designers*

5. **Design products accessible to the widest possible user group,** recognising the increased prevalence of DSI and that in later life DSI is often accompanied by co-morbidities.
   - *Challenge developers and designers to work with older people with DSI to develop products,* making incentive funding available to support this, and showcase the best results at an annual national event.

   - *Test new technology products* with older people with DSI *who have a range of different co-morbidities.*

   - *Establish an open platform* where providers, manufacturers and developers *can showcase products* and share, receive and respond to user feedback, accessible to all.

1. Introduction

The study was commissioned in 2014 by Sense, the national charity for dual sensory impaired (DSI) and deafblind people, to explore the situation of older people using telecare and assistive technology with a communication function within its client group.

The context for the project

- Recent decades have seen rapid developments in telecare and other forms of technology, particularly equipment designed for older people living independently.
- In all parts of the UK, policies have been developed to encourage the production and distribution of telecare and assistive technology devices. Local authority commissioning has played a major role in this, but a private market has also emerged and some voluntary organisations now supply and advise on this type of equipment.
- Growing numbers of people with DSI are living in the community, about 70% of them aged over 70. By 2030, the UK is likely to have 570,000 people with DSI, including 418,000 aged over 70 and 245,000 with severe impairments.

Existing knowledge about telecare, technology and older people with DSI

- A search of the academic literature on telecare and assistive technology was undertaken as the study began. This found only 10 articles, all published in 2004-2014, had reported studies of older people with DSI and their use of technology.
- The broader literature on disability and assistive technology distinguishes between people with acquired and congenital disabilities; one review of the literature found that people in the latter group were more likely to report successful use of technology.
- As few researchers had previously examined technology use in the everyday lives of older people with DSI, the new study was timely and potentially important.

Research methods

- The new study used the Everyday Life Analysis (ELA) method developed for the AKTIVE project; it employs qualitative techniques and engages with

participants over an extended period. The method was adapted to accommodate the communication needs of older people with DSI and aimed to recruit 40 people.

- Recruitment was via Sense local forums, supplemented by approaches to DSI teams in some local authorities and other voluntary organisations. 43 people joined the study; 38 remained in it long enough to permit ELA analysis.

- The ELA method involves repeat household visits and uses observation, interviews and other qualitative techniques. 146 household visits were completed with 38 participants; another family member, carer or other person was present during 59 of these visits.

Characteristics of study participants

- Study participants included 21 men and 17 women. 20 lived alone; 23 were aged 80+. 15 had severe DSI; 15 severe visual/moderate hearing impairment; 3 had severe hearing/moderate visual impairment; and 5 had moderate DSI. 20 had other serious illnesses/disabilities, and 34 had some care from a family member.

Data collection and analysis

- Three researchers undertook the fieldwork in various localities in England in the South East, North and South & Midlands; the same researcher conducted all visits with each participant. Data was subjected to computer-aided analysis and conducted collaboratively with support from the principal investigator and study Advisory Group.

2. Technology and older people with dual sensory impairment

Types of equipment available in participants' homes

- The range of equipment available to participants included five categories of equipment, using a categorisation developed during data analysis.

- 29 people had 'Alerting Technology' items (mostly pendant alarms); 13 had items of 'Assistive Listening Technology', in most cases a hearing loop; 23 had at least one item of 'Visual Impairment Equipment'; 10 had 'Specialist equipment for using ICT'; and 13 had one or more 'Assistive Telecommunications Device'.

Equipment supply

- Most telecare and 'alerting technology' had been supplied by local authorities. Few people with telecare had more than the basic, 'first generation', telecare device, a pendant alarm linked 24/7 to a monitoring centre.

- Some participants reported difficulty in obtaining a specialist DSI assessment and some felt their assessment had not adequately addressed what they wanted to achieve, as it had focused almost exclusively on risk and safety.

- A few people had been referred to social services by the NHS, which had also supplied some with hearing aids, magnifiers and talking blood glucose monitors.

- Voluntary organisations had been a source of equipment, support and advice relating to technology for some participants; most were happy with this service and some had received equipment on loan. Some organisations offered a wide range of equipment, training courses, home visits and bespoke assistance.

- Many people had purchased some equipment privately, some after reviewing equipment at special exhibitions. Many felt anxious about purchasing expensive items and would have liked independent advice which was not available.

3. Sensory impairment, ageing and technology

Everyday life for older people with DSI

- Study participants faced difficulties in three main areas of everyday life: when walking, using public transport or other activities *outside the home; in their home environment,* where some struggled with daily tasks; and in their *communications with others,* including friends, families, support workers and professionals.

- All had DSI, in some cases severely affecting both their hearing and vision; others had moderate impairment in one or both these senses.

- Some had coped well with single sensory impairment for many years and were now adjusting to the deterioration of the other sense on which they had previously relied.

- Others were also coping with other health conditions or disabilities which affected their mobility, strength, dexterity, balance, energy or mood.

Challenges outside the home environment

- Outside the home, accessible GPS devices enabled some participants to continue to travel and access activities.
- Technology helped some participants in managing errands, journeys and routines, but some felt it changed the nature of some activities, such as shopping and socialising, which when carried out online were experienced differently.

Challenges within the home

- Within the home, technology helped some people with their leisure pursuits such as reading and cooking, but there were few examples of technological solutions being applied to other daily activities, such as cleaning or gardening.
- Technology supported some people to manage personal administration and finances, offering valued privacy and autonomy. Some devices such as audible scanners and Braille note-takers were expensive and out of reach for some.

Communication, care roles and relationships

- Technology made a positive difference for some, but not all, participants in their communication and relationships.
- Some had technology which enabled them to use email and social media, and now had 'email friends' with whom they were in regular contact.
- A few used technology in interactions with their grandchildren.
- Some people in the study used technology to address communication difficulties in receiving or providing care.
- Some said technology did not enhance 'social' activities enough to compensate for lost social interactions, or the difficulty of managing face-to-face encounters.
- Telecare and alerting technologies improved relationships for some by reducing concern about risk, particularly if families were anxious about their safety.
- Loop systems, specialist phones and accessibility software for use with computers were used by some, although some people had difficulty with these.

4. Barriers to using technology

Four types of barriers were identified by participants in accessing or using technology, including:

Perceptions and attitudes

- Some people in the study were sceptical or concerned about using telecare or assistive technology, arising from their general fears or views about technology; past, negative experiences with equipment or machinery; and a perception that technology was a signifier of vulnerability, or would be stigmatising.
- Some feared coming to depend on technology; others felt they were 'too old' to learn, or expressed a preference for human rather than technological assistance.
- By contrast, some participants were 'enthusiasts' for technology, who said they had always been interested in, or always liked technology, were keen to use new things and felt confident and competent when doing so.

Awareness of telecare and technology

- Limited awareness of what equipment existed, might be suitable or could be obtained was a widespread problem; many people did not know how to find reliable information or obtain advice.
- Family members or care workers were willing to help people find out about or use technology, but often lacked knowledge or information about how to do this.
- A few older people were well supported by family members with specialist knowledge, although help from younger people could be *'too quick'* to learn from.
- Some people had obtained good information and support from voluntary organisations offering specialist services for people with DSI. Choosing the right option was difficult, however, and could be a source of anxiety.
- There was a widespread view that an independent advice service, specifically for older people with DSI, was needed and would be valuable.

Cost and choice

- Cost was a major barrier to access for most people in the study. Many were confused by variations in price and the different products available on the

private market; some chose not to purchase anything as they lacked confidence in the suitability and appropriate price of items available to buy.

- A few people said they felt 'lucky' they could afford to buy the things they needed. Most had to think very carefully about expensive items, as they needed to use their Direct Payments, Attendance Allowance or Disability Living Allowance to cover the cost and felt they could not afford to make mistakes.

- Some people said their local authorities offered a very limited range of products, or focused only on risk, ignoring other equipment they might need or want.

Fit for purpose?

- Many people said that available equipment did not meet their needs and that they felt forced to 'compromise'. As products for people with sensory impairments often rely on using another sense in a compensatory way, much equipment was not really suitable for people with DSI. Some felt most developers and designers had not created products with older people with DSI in mind.

- Many people had equipment they could not use, had put aside, or could not locate, including mobile phones, pull-cords, pendant alarms, hearing aids, sensors and software.

- Older people with DSI are especially likely to experience changes in their impairments or other aspects of their health, so products need to respond to this. As abilities change, reassessment, individual support and follow-up are vital.

- Many people had lacked guidance on using equipment when it was first supplied, if they encountered difficulties, or when their circumstances changed.

- Some people who had attended training courses felt these were not really suitable for people with DSI and that bespoke, individual support was needed.

5. Conclusions and recommendations

Conclusions

- Service providers, equipment suppliers and product developers need to do much more to meet the diverse needs of rising numbers of older people with DSI.

- Equipment will become more varied and sophisticated in future. It must address the needs of older people with DSI; good systems for assessing needs, providing access to equipment and supporting use will be needed to assist them in using it.
- Negative attitudes were a factor, but not the main impediment, to effective use of technology for most older people with DSI in the study.
- Limited knowledge and low awareness of available equipment and technology, and a lack of information about how to obtain it, were common problems.
- Few items of equipment had been designed for people with DSI, suggesting designers and developers may not appreciate that in older people, DSI is often accompanied by difficulties with manual dexterity, balance, mobility and stability.
- 'Success stories' included people for whom technology meant they felt much safer at home; were using public transport alone; could manage everyday chores unaided; and enjoyed new modes of communication and social interactions.

Limitations of the study

- The study was small scale, relied on agencies in touch with its target group for recruitment and therefore may not be representative of all older people with DSI. Participants' accounts could not be checked with other sources. The timeframe meant that the project could not assess longer-term consequences and the findings are based on a group who were comparatively positive about technology.

Issues for future research

- New studies of older people with DSI are urgently required. Qualitative methods should form part of these due to their complex circumstances. Future research should be larger-scale, should study people with and without technology in place, and include some who would be introduced to technology during the study. Studies are also needed of agencies working with older people with DSI to understand the issues they face.

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