



**sense**  
for deafblind people

# **Keeping in Touch with Technology?**

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

Kate Hamblin, Emma-Reetta Koivunen & Sue Yeandle

The research grant for the study reported in this publication, directed by Principal Investigator (PI) Professor Sue Yeandle, was awarded to the University of Leeds in 2014 to conduct the study in collaboration with the Oxford Institute of Population Ageing, University of Oxford. The authors of the report gratefully acknowledge the support of the research sponsor, Sense, and of the University of Leeds in this research. The report was completed in November 2015 and published in February 2016, after the PI's move to the University of Sheffield in October 2015.

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# Preface

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The findings presented in this report are based on a study commissioned by Sense in 2014 and completed in 2015. The authors wish to thank everyone at Sense, especially Anna McGee, Head of Research, for their support and advice throughout the study. Many other organisations and agencies assisted in recruiting study participants; we are very grateful for all the help they provided. Our warmest thanks go to the men and women with dual sensory impairment who participated in the study, who were so generous with their time and allowed the researchers to visit them at home over an extended period.

The study team included three experienced researchers who undertook the fieldwork and data analysis and provided specialist expertise in technology, older people and dual sensory impairment: Kate Hamblin (University of Oxford); Kara Jarrold (Sense) and Emma-Reetta Koivunen (then at the University of Leeds). The team wishes to thank members of the Advisory Group which gave expert guidance throughout: external member Lizzie Coates (University of Sheffield) and Sense staff Ann Copson, Donna Corrigan and Nicola Venus-Balgobin. The study was directed by principal investigator Sue Yeandle.

## About the study team

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**Kara Jarrold** is Head of Arts and Wellbeing at Sense, the national charity for people with multi-sensory impairments, and a social researcher who uses qualitative methodologies to explore everyday experiences in relation to sensory impairment, ageing, technology and creativity. Her research interests include ageing and identity, care and caring, sensory accessibility and the role of culture, heritage and arts in health promotion and social inclusion for disabled and older people.

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**Professor Sue Yeandle** is Director of CIRCLE (Centre for International Research on Care, Labour and Equalities), University of Sheffield. Formerly at the University of Leeds, Sue has led many studies of carers, older people and the support they need, and has published widely on social care, technology, gender and public policy.

# Executive Summary

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## 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.

## **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.

## **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.

## 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.

## 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.

## **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.

# Chapter 1 | Introduction

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## Chapter summary

- *Telecare and assistive technologies are on the policy agenda as a potential means of supporting growing numbers of people requiring care.*
- *The incidence of dual sensory impairment (DSI) rises with age, so ageing societies will see increasing numbers of people with DSI.*
- *DSI presents different challenges from single sensory impairment; ageing with DSI can make activities of daily living difficult and increase social isolation.*
- *Despite rising numbers of older people with DSI, and an increased policy focus on telecare, there is limited research on technology use by this group.*
- *The project was commissioned by Sense to address this gap and to explore the use of telecare and assistive technology by older people with DSI.*
- *The study included 146 longitudinal, in-depth interviews with 38 people with DSI over the age of 60.*

The aim of the study reported here was to develop a clearer understanding of the preferences, attitudes and experiences of older people with dual sensory impairment (DSI) in relation to telecare and other assistive technology with a communication function, and to make this knowledge available to help improve the delivery, design and support available to older people with DSI using equipment in these categories.

## The context for the project

The study was commissioned by the national charity, Sense, which supports and campaigns for children and adults who are deafblind or who have sensory impairments. Sense commissioned the study in summer 2014 to explore the specific situation of older people within its client group, having become aware of previous research undertaken by the present authors within a separate project, 'AKTIVE'. Funded by the UK Technology Strategy Board<sup>1</sup>, AKTIVE also explored telecare and technology use by older people, focusing on those at risk of falls or with memory problems, but did not include people with DSI.

As explained elsewhere, recent decades have seen rapid developments in telecare<sup>2</sup> and other forms of technology designed to assist older and disabled people to live independently in the community, and a variety of policy initiatives have been implemented at national and local level in the UK to promote its wider and more effective use (AKTIVE Consortium 2013). Some studies have reported frustration at the limited use being made of the growing range of available equipment, and the widely reported difficulties older and disabled people and their families have in knowing what equipment is available and how to obtain and use it.

There has also been growing awareness in recent years of the specific needs of older people with DSI, and of their rising numbers. Of the three groups of people with DSI (those with congenital DSI, those with congenital visual or hearing impairment who later acquire hearing or visual impairment, and those with acquired hearing and visual impairments), older people make up a large proportion of the latter group, as both sight and hearing decline with age<sup>3</sup>. A loss of hearing and deteriorating sight in older age is often seen as a 'normal' aspect of ageing, rather than a disability, and under-recorded by local authorities, so figures on people with DSI are likely to be under-estimates (Scharf et al. 2007).<sup>4</sup> It is thought that about 350,000 people in the UK experience DSI and that about two-thirds are over 70; some 132,000 are estimated to have severe impairments. The number of people with DSI is expected to increase in future with population ageing and increased longevity. By 2030, the numbers of people with DSI are expected to reach 570,000, to include about 418,000 people aged 70 or older and to comprise 245,000 people with severe impairments (Robertson & Emerson 2010).

The dual impairment of both sight and hearing presents specific challenges (compared with single-sensory impairment) often requiring additional support, as it reduces '*biological resources and capacities for adaptation*' (Brennan & Bally 2007: 284) and '*because it interferes with (the) ability to compensate for one primary sensory modality with the other*'. Learned skills, such as lip-reading, may also be undermined if a person's sight deteriorates. Scharf et al. (2007) argue that isolation is also linked to DSI, as a person with DSI may withdraw through inability to participate in 'regular' conversation, and tends to engage in more solitary leisure pursuits. One study found a third of people aged over 75 with DSI wanted more social contact, compared with about a fifth of people without impairment (Crews & Campbell 2004). Compared with people with a single, or no, sensory impairment, people with DSI were also less likely to socialise with friends, go out to restaurants, attend church or go to the cinema. In studies, people with



DSI have had more difficulty carrying out some activities (IADLs<sup>5</sup>) than those with a single-sensory impairment, including preparing meals, shopping and using the phone (Brennan et al. 2005; 2006), and dressing and getting in and out of a bed or a chair (Campbell et al. 1999). Scharf et al. (2007) claim DSI also presents additional risks by making a person more physically vulnerable to hazards and falls.

The rising numbers of people with DSI, the fact that policymakers and professionals increasingly propose telecare and assistive technology as ways of addressing strains in the health and social care system, and the relative absence of research on older people with DSI combine to make the new study timely and potentially important.

The report is organised as follows: the present chapter introduces the study, describing its background, the prior state of knowledge, the methods used in the new study and the older people with DSI who participated in the research. Chapter 2 describes the technology available to those participating in the study and explains how they had obtained it. Chapter 3 examines how people in the study were using technology inside and outside the home and in their communications and relationships with other people. Chapter 4 explores barriers to technology use by older people with DSI, addressing perceptions and attitudes, awareness of available options, issues of cost and choice and of the suitability of equipment. Chapter 5 concludes the report, presenting the conclusions of the study and making policy recommendations based on its findings.

### **Existing knowledge about telecare, technology and older people with DSI**

To ensure that existing knowledge of telecare, technology and older people with DSI was taken into account in developing and planning the new research, the project began with a search of publications databases.<sup>6</sup> This found that although numerous peer-reviewed articles on telecare and assistive technology had been published in academic journals, few addressed the needs, circumstances, experiences or aspirations of older people with DSI. This group had been ignored or missed in some studies and excluded from others. One systematic review of older people's use of assistive technology found older people with impairments, including those with visual or hearing problems, had been excluded from 26 of 68 studies of the impact of telecare and telemedicine (van den Berg et al. 2012).

The initial search undertaken was for one of the terms 'assistive technology'

or 'telecare' in combination with one of the terms 'deaf blind' or 'dual sensory impairment' in the title, keywords or abstract of an article. This produced very few results for 'assistive technology' and only one for 'telecare'. A subsequent search, for 'telecare' or 'assistive technology' combined with one of the four terms 'hearing', 'deaf', 'visual' or 'blind', produced rather more results (see Appendix 1, Table 1). If an article appeared to be of interest, its abstract was read to confirm this<sup>7</sup>; lists of references were also examined in relevant cases. In total, 10 articles relevant<sup>8</sup> to older people with DSI and/or including the phrase deaf-blind were found, all published between 2004 and 2014, indicating that very little research on the use of telecare and assistive technology by people with DSI had been published, a point also noted by Kricos (2007).

Although the search found some articles which included information about people who were deaf or blind (e.g. Fellbaum & Koroupetroglou 2008), the findings reported in them did not address the situation of people with DSI. Other articles described the results of pilot studies or trials of new assistive technology products: one reported a pilot of new refreshable fingerspelling technology (Kindiroglu et al. 2012); Sarkar et al. (2013) examined Braille displays; and Vincent et al. (2014) covered new navigation devices. Such articles typically reported small-scale pilots, some conducted by product designers, or described a specific product.

One article (aimed at audiologists) on assistive technology, assessment and service provision concluded: *'there are no one-size-fits-all solutions for fitting hearing assistive technology for individuals with dual sensory loss'* (Kricos 2007: 279) and recommended that audiologists should seek advice from colleagues specialising in sight loss when assessing the needs of a person with DSI. The finding in a subsequent study of people with DSI (Schneider et al. 2014), that 40% of study participants felt their audiologist was unaware of their visual impairment, suggests that implementing this recommendation may not be easy.

One of the few studies to include people with DSI examined the use of assistive technology devices among 131 people aged over 65 in Sweden (Eklund & Dahlin-Ivanoff 2007). Participants in this study were randomly assigned to a health promotion programme or to a tailored, individualised programme. The technology included in the study was divided into non-optical (such as tape-recorders, signature-frame and slicing aids), or optical (such as hand or stand magnifiers and reading glasses). Those on the health promotion programme were found to have been prescribed technology to assist with low vision and with activities

of daily living (ADLs); most of those on the individualised programme received technology for low vision only. The study found that after 28 months the number of devices a person with DSI had made no difference to their ability to perform activities of everyday life. Based on their finding that assistive devices alone did not contribute to maintaining ADL performance, the authors recommended that assistive technology should be part of a broader range of support available to people with DSI.

Outside the search for literature on DSI and technology, and in contrast to the lack of research on this, a growing body of empirical evidence has focused on how people with (sometimes unspecified) disabilities use telecare and assistive technology. This often distinguishes between those with acquired, degenerative and congenital disabilities and, as such, has some relevance to the present study. A review of the literature available prior to 2002 concluded that people with congenital disabilities were more likely than other disabled people to report successful use of telecare and assistive technology (Pape et al. 2002) and tended to see technology as a route to greater independence. By contrast, people with degenerative disorders often used telecare and assistive technology mainly to continue previous activities, or to control symptoms. The review concluded that, compared with people with acquired disabilities, people born with disabilities learn to shape meanings associated with assistive technology at an early age and consequently develop different coping strategies; the technologies are ascribed meanings which do not interfere with their identities. People with acquired disabilities, however, could use assistive technology to reduce the impacts of environmental barriers, their own impairments and / or any other disabilities or health problems they develop, although in some examples in the literature assistive technology devices were found to threaten a user's identity or sense of self. Pape et al. concluded that while technology can reduce some of the barriers faced by people with impairments, personal factors affect the meanings they attribute to it and inhibit their effective use of it.

Some of the people studied in the literature reviewed associated telecare and other assistive technology with social stigma and saw it as signifying illness, disability, ageing or a lack of competence, a finding subsequently echoed in the AKTIVE study (Hamblin 2014).

The finding that some older people 'trade-off' their reluctance to use technology against their fear of other changes (such as giving up their home) and that this affects their use and acceptance of different devices calls for research which can

gain insight into how older people with DSI make decisions. The research design and methods used in this study (described below) were selected to achieve this. In establishing the state of existing knowledge about older people with DSI and technology, the literature review identified a report commissioned from the University of Stirling by the Scottish Joint Improvement Team. This offered a recent and useful overview (Kerr et al. 2011). Aimed at assessors, care and support staff and their managers, telecare service managers and development staff, it provided reasonably up-to-date information on the type of technologies available for people with DSI; covered assessment, rights and ethics; provided case studies; and addressed training issues for professionals engaging with people with DSI.

The team also reviewed material published, or made available, by the study sponsors, Sense<sup>9</sup>, which has staff with specialist expertise in supporting people with DSI and provides advice and guidance to them and those who work with, or support, them. This material and the Kerr et al. review yielded an initial categorisation of the equipment available for older people with DSI (Box 1.1).

This informed the design of the topic guides for the study (described below) and prior to the start of fieldwork helped orient the research team to the assistive technology available to and used by people with DSI. The categorisation was broadly relevant and applicable to the technology and equipment in the homes of participants in the new study, although (as explained in Chapter 2), some differences were found.

The literature review showed the new study was being developed at a time when, despite many different telecare and communication aids being (theoretically) available to older people with DSI, and much assistive and other technology being potentially adaptable for their use, little research had been published on how people in this specific group were using it. Few academic researchers had explored how it was being used in everyday life, although useful categorisations and information on available technology had been drawn together by specialist advisers and in publications for policy / practitioner audiences.

The chapter now describes the research methods used in the study to examine the everyday life experiences of a sample of older people with DSI who could be studied over time and summarises the characteristics of those who took part.

## Box 1.1 Telecare and assistive technology available for older people with DSI

Technology type	Purpose of the equipment
<b><i>Aids for travel and leisure</i></b>	<ul style="list-style-type: none"> <li>• GPS technology to assist with navigation outside the home</li> <li>• Sensors which vibrate when an obstacle is approached</li> <li>• Reading aids (e.g. electronic or audio books; devices which can be connected to a refreshable braille display).</li> </ul>
<b><i>Aids for using ICT</i></b>	<p><b><i>For people with a visual impairment</i></b></p> <ul style="list-style-type: none"> <li>• Software packages to assist with computer use (enlarging text, using voice activation or reading text aloud)</li> <li>• Braille displays to read documents/use the Internet with word processing programmes, e.g. braille note-takers (personal digital assistants, like a smartphone without phone functionality)</li> </ul> <p><b><i>For those with hearing impairment</i></b></p> <ul style="list-style-type: none"> <li>• Web clips on websites using British Sign Language (BSL)</li> <li>• Remote interpreting using a webcam (a Sign Language Interpreter translates remotely for a hearing impaired person, by appointment).</li> </ul>
<b><i>Aids for communication</i></b>	<p><b><i>For people with hearing impairment</i></b></p> <ul style="list-style-type: none"> <li>• Wired and wireless hearing loops</li> <li>• Personal listeners (hand-held battery-operated devices which amplify sound) for use in social situations or noisy environments</li> <li>• Textphones and screenphones which display conversation in text form enabling the user to lip read or use sign language (and can be connected to flashing beacons)</li> <li>• Braille note-takers (these can be used as textphones if connected to a phone line)</li> <li>• Smartphones can help people with DSI<sup>10</sup> via haptic feedback using touch, vibrations and voice control</li> <li>• Specialist apps (used with Smartphones) which employ GPS, cameras and other features to assist people with DSI with navigation<sup>11</sup> and identification<sup>12</sup>.</li> </ul>
<b><i>Aids for the home environment</i></b>	<ul style="list-style-type: none"> <li>• Telecare devices, used to summon help or detect changes and risks (e.g. fall detectors or environmental sensors connected to a remote monitoring centre or person in another location)</li> <li>• Environmental alert systems for use in the home (e.g. vibrating pagers, watches or pads; flashing beacons linked to doorbells, fire alarms or phones; clocks with vibrating alerts/flashing lights; 'talking' microwaves which 'speak' the various settings)</li> <li>• Sensors for use with crockery to avoid spillages which indicate, via vibrations, if cups, jugs, etc. are almost full.</li> </ul>

Source: Kerr et al. (2011) and [www.sense.org.uk](http://www.sense.org.uk)

## Research methods

The project used a method called Everyday Life Analysis (ELA), which the study team had developed in the AKTIVE project to gain insights into the daily lives of older people, their aspirations and frustrations, and their engagement with telecare. This method employs a variety of qualitative research techniques and engages with study participants over an extended period of time to produce a rounded account of their experiences, perceptions and circumstances.

For the present study, the approach was adapted to the specific situation of people with DSI and to deliver the study within the timescale and resources available. Research contact was planned with each study participant over four household visits, each at intervals of 4-6 weeks within a total period of 6-9 months.<sup>13</sup> This 'longitudinal' approach was chosen to help researchers obtain an in-depth account, to observe change over time, and to enable the research team to develop rapport and trust with study participants, responding appropriately to their communication needs.

The method involves collecting data about participants' daily lives, relationships and circumstances as well as about the telecare and technology they have available, or use.<sup>14</sup> It uses interviews, conversation, observational and other specific techniques chosen because of their suitability for use with the target group. In this study, observational data was particularly important. Each researcher recorded her observations immediately after each household visit, using a field-note template which included: expectations prior to the research visit (based on initial contact and information); a brief account of the visit; notes about issues relevant to the study's main research questions; reflections on how the technology or telecare was being used; and topics to be further explored in subsequent visits. The data available for analysis thus did not emerge purely from the research interviews and conversations, but where applicable also included observations about the participants' homes and interactions with other people present, such as any family/friend carers or paid care workers.

Each household visit included a semi-structured interview focused on a specific theme. The first focused on biographical information, the equipment or technology available to the older person and how they had acquired it. Each subsequent visit included discussion of events since the previous encounter, and of how the telecare equipment or assistive technology available was being used. The second, third and fourth visits focused, in turn, on social networks and relationships; homes and

local areas; and health and well-being. Where it was not possible to complete four visits, the topic guides for visits three and four were combined.<sup>15</sup>

In total, 146 household visits were conducted, 87 when the older person was alone and 59 when a carer or relative was present - of these, 31 became joint-interviews (Table 1.1). The latter enabled the other person present to help the older person with DSI answer questions. This was useful in some cases of communication difficulties and provided insight into dynamics, interactions and relationships (Arksey 1996; Seymour et al. 1995; Valentine 1999). One participant's family member translated the questions using Deafblind Manual.

Participants in the study were also invited to contribute to the study by completing diaries in their chosen format (audio, hand or type-written); eight chose to do this. Diaries are useful in recording perceptions and events (Butcher & Eldridge 1990; Keleher & Verrinder 2003), facilitating research with people for whom communication is difficult (Milligan et al. 2005) and enabling participants to contribute on their own terms (Spowart & Nairn 2013). The diaries produced insight into events which occurred between visits and participants' experiences with their equipment.

**Table 1.1**

**Everyday Life Analysis of Older People with DSI: fieldwork data by region numbers**

Fieldwork	North	South & Midlands	South East	All
<b>Research participants included in ELA analysis</b>	14	15	9	38
Research participants supported by a carer (family member or friend)	13	14	7	34
Carers 'involved' in the project	9	8	4	21
Carers included in joint interviews	5	6	4	15
Carers interviewed separately	0	1	1	2
Carers observed	8	4	5	17
<b>Cases with no contact with a carer</b>	7	7	3	17
<b>Number of ELA household visits</b>	51	60	35	146
Visits where carers were observed	10	12	6	28
Visits with carers in joint interviews	9	18	4	31
<b>Participants completing diaries</b>	2	3	3	8

Source: SENSE study database, Universities of Leeds & Oxford, 2015.

## Research participants

The research participants lived in different locations in England and were recruited by researchers based in Oxford, Leeds and London. As older people with DSI are a difficult target group to identify, initial recruitment to the study (target, 40 participants) was through the sponsor (Sense) which provided access to its local forums for people with DSI and its contacts, groups and newsletter. Recruitment via these means did not produce the sample numbers required and therefore the team also used other methods, including approaching local authority DSI and sensory teams, local and national blind and deaf groups and carers' / older people's organisations; placing publicity in local newspapers and recruiting through research participants (the 'snowball' method).

To take part in the study, participants needed to be over age 60, have some degree of both hearing and visual impairment, live in the community and have relevant technology. The latter included telecare and other technologies with a communication function enabling them to send a message to others (e.g. a pendant alarm or computer screen magnifier) or to receive information (e.g. a liquid level indicator, pen reader, or flashing beacon connected to a doorbell).

In total, 43 research participants were recruited to the study; 38 met the criteria for inclusion in the final Everyday Life Analysis (already described) and 33 completed all four research visits.<sup>16</sup> The five people who withdrew after the first visit did so because of changes in their health or other circumstances.

The final sample included 21 men and 17 women. Half the participants were widowed (19), while 13 were married, three divorced and three single. Twenty participants lived alone. Of the 18 living with others, 13 lived with a partner and the others with an adult child or children, a sibling or ex-partner. One participant also had a live-in care worker.

Many participants were advanced in age: most (23) were over 80, and 12 of these were in their 90s, including two participants aged 99. All others were in their 60s (8) or 70s (6), apart from one who was included despite being in his late 50s.<sup>17</sup>

Research participants' dual sensory impairments were varied. Based on their accounts and the researchers' observations, they were classified as having *severe dual sensory impairment* (15 participants), *severe visual impairment with moderate hearing impairment* (15 participants), *severe hearing impairment with moderate*



*visual impairment* (3 participants), and *moderate visual and hearing impairment* (5 participants). Among those with severe DSI, some had congenital conditions (e.g. Usher syndrome); others had congenital visual or hearing impairment (e.g. Charles Bonnet syndrome) and had acquired their hearing or visual impairment in later life, often as macular degeneration. Most research participants possessed hearing aids, but not all felt these were helpful and some did not use them regularly.

Within the study, 20 participants also had other serious or debilitating illnesses or disabilities, such as Parkinson's disease, cancer, arthritis, heart disease or heart problems, and depression (see appendix, Table A2); six had serious mobility difficulties or used a wheelchair.

Some relied on care workers or family carers to help them move around in their own homes. Only four research participants said they had no-one who supported them unpaid or who was their carer. The rest, 34 people, named as their carer their spouse, an adult child, or other member of their extended family (e.g. grandchildren, nephew) or a friend. Six people in the study had a guide dog. Other types of support included care workers (11 participants) and communication guides (9 people).

The household visits were undertaken by three experienced fieldworkers (Kate Hamblin, Kara Jarrold and Emma-Reetta Koivunen) between September 2014 and June 2015. The data collected were analysed collaboratively with the aid of NVivo computer software. The research team was led by Sue Yeandle (as principal investigator) and supported throughout by an Advisory Group which met on three occasions and included experts in DSI, an external academic adviser, and members of staff at Sense, including some with personal experience of DSI. Fieldwork staff undertook training in DSI arranged by Sense prior to entering the field to collect research data, and liaised extensively with DSI forums and local groups in developing and implementing the study.

# Chapter 2 | Technology and Older People with Dual Sensory Impairment

## Chapter summary

- *The term ‘telecare’ did not resonate with most participants; ‘assistive technology’ had greater recognition and salience.*
- *Five broad categories of equipment were identified: alerting technologies (29 participants), assistive listening technologies (13 participants), visual impairment equipment (23 participants), ICT equipment (10 participants) and tele-communications (13 participants).*
- *Equipment was supplied by local authorities, the NHS, some other publicly funded agencies, third sector organisations and through private purchase.*

This chapter sets the scene for the analysis presented in Chapters 3 and 4 by summarising the equipment available to the 38 study participants and explaining the main ways in which they had acquired it.

## Equipment available in participants’ homes

When the study began, the project planned to focus on people with DSI with telecare in place. Early on, however, the team found the term ‘telecare’ was not resonating with either potential study participants or those assisting the researchers with recruitment. It also became apparent that focusing exclusively on telecare (technology linked to a monitoring centre and used to summon assistance when triggered by a user, or when a hazard was detected in the home) would prevent the team from capturing experience of the many other technologies which people with DSI were using to help them lead fulfilling and independent lives.

It was thus decided to expand the inclusion criteria to embrace also participants with other technology or equipment supplied to assist them with communication, either by enabling them to communicate a message to others (using a pendant alarm or computer screen magnifier, for example) or to receive information (such as a liquid level indicator, pen reader, or flashing beacon connected to a doorbell). Publicity for the study was adjusted to indicate that potential participants should be *‘using some form of technology that supports them in or outside their home; (examples might be a pendant alarm, a smoke alarm connected to a response centre, an automatic gas shut-off, or a GPS device)’*.

The full range of telecare and technology with a communication function used by the 38 study participants is shown in Table 2.1, which includes equipment some participants had acquired by the time the study ended but did not have when it began. Some participants had the same equipment throughout the study, while others seemed to have a new device at every visit. During visits, participants often spoke about devices they no longer used or had returned or discarded.

**Table 2.1**

**Participants' telecare and assistive technology with a communication function**

Type of AT	Specific AT	Incidence
<b>Alerting technologies</b> <i>29 participants</i>	Pendant alarm	24
	Pull cords	6
	Vibrating pillow alert	5
	Smoke alarm linked to monitoring centre / fire service	3
	Smoke alarm with flashing beacons	1
	Flashing beacon for doorbell	1
	Bogus caller alarm	1
	Vibrating smoke alarm	1
	PIR sensor linked to pager / vibrating wristband	1
	Carbon monoxide detector linked to monitoring centre	1
	Security alarm with beacon	1
	Medication reminder	1
<b>Assistive listening technologies</b> <i>13 participants</i>	Hearing loop	11
	Phone amplifier	1
	Doorbell amplifier	1
	Amplifier for TV	1
	Bone conducting headphones	1
<b>Visual impairment equipment</b> <i>23 participants</i>	Talking books / papers and accessible audio player	11
	Electronic magnifiers	8
	Liquid level indicator	7
	Talking watch	6
	Talking scales	6
	Talking cooking timers	3
	Talking clock	3
	Talking labelling device	3
	Talking microwave	3
	Colour detector	3
	Talking blood sugar monitor	2
	Talking oven	1
	Talking jug	1
	Talking meat thermometer	1
<b>ICT equipment</b> <i>10 participants</i>	Accessibility software	8
	Braille display	3
	Braille notetaker	2
<b>Tele-communications</b> <i>13 participants</i>	Specialist phone	10
	Textphone	1

All technology available to participants in their homes is included in Table 2.1, even if it was rarely, or never, used. One respondent alerted the team to the fact that retained (but unused) equipment, as distinct from discarded items, may come into use at a future date. Mrs Crane, who was 83, had severe DSI and had been supplied with a liquid level indicator. During the first household visit she said she '*never used*' this, as she preferred to shine a bright light when making a hot drink. During the study, however, her condition changed, and bright lights became intolerable; she then began to find the liquid level indicator useful and to use it.

The types of specialist technology seen in participants' homes fell into five main categories<sup>19</sup>, similar to those indicated in Chapter 1, but with some differences. Each is discussed in the paragraphs which follow and outlined in Table 2.1. Our rationale in departing from the schema for categorising technology outlined in Chapter 1 is that, at least in terms of how participants chose to use it, some technology was multi-functional. Thus Braille displays were used for leisure activities such as reading, but also enabled some participants to use ICT equipment and communicate using email. The research team also quickly learned that some equipment, for example colour readers, did not neatly fit into any of the categories identified based on previous studies and research.

*Alerting technologies* are designed either to summon the help of others (as in the case of pendant alarms), to alert the user to a hazard, or to let them know that something or someone requires their attention (such as flashing beacons for smoke alarms or doorbells). These technologies include, but are not confined to, telecare technologies. Of the 38 research participants recruited, over half (24) had some form of telecare by the end of the project; all of these had a pendant alarm, although very few (3) had any additional telecare equipment.<sup>20</sup> The team was surprised so few of those with basic telecare had no equipment beyond the pendant alarm, as there are many telecare devices available to detect hazards in the home, and the continuous direct link they provide to a response centre is potentially very suitable for someone whose sensory impairments may leave them unaware of hazards in their home environment.

In total, 29 participants had some form of alerting equipment; some had more than one device, and in all 46 pieces of equipment were identified. These included: smoke alarms with flashing beacons (1 participant); doorbells with flashing beacons (1 participant); an infra-red alert for property entrance linked to a vibrating wristband (1 participant); a burglar alarm with flashing beacon (1

participant); vibrating smoke alarms (1); vibrating pillow alerts (5); and pull cords in the property (6 participants).

The second category of technology observed comprised *assistive listening technologies*, such as hearing loops (both personal and for watching television) and amplifiers for telephones, doorbells and TVs. In all, 13 participants had some form of assistive technology for listening. Eleven of these had loops, and a total of 15 devices were reported. Hearing aids (not shown in Table 2.1) are related to this category, and 32 participants had these, among whom 27 regularly wore their hearing aid(s).

As 30 people in the study had severe sight impairments (compared with 18 with severe hearing impairments), it is unsurprising that more participants (23) had *visual impairment equipment*, including 11 who had talking books and / or newspapers. Despite their cost, eight participants had electronic magnifiers<sup>21</sup>; seven had liquid level indicators (several of which had been provided to participants by one local third sector organisation); some (<10) had talking watches and clocks; and others had audible devices for cooking, such as ovens, microwaves, meat thermometers, jugs and timers.

A fourth category was *specialist equipment for using ICT*. Ten participants had items such as Braille note-takers and displays and / or specialist accessibility software. Despite their cost, three participants used these.<sup>22</sup> *Assistive telecommunication devices*, the fifth category, comprised specialist phones and textphones, which 11 participants had in their homes.

In the study, we were particularly interested in how participants had come to have particular devices available at home and in who supplied these; if they incurred any costs in accessing or using them; and if they felt they had been appropriately consulted in their choice. As part of our findings relevant to these issues, the next section looks at the agencies providing advice, support and equipment.

## **Equipment supply**

Participants in the study lived in different localities in England, as described in Chapter 1, and had access to a variety of equipment which they had acquired in many different ways. Some had obtained the devices through their local authority, others had accessed some or all of their equipment through the NHS, or their local fire service, and some had obtained it, or specific items of equipment, through one

of the voluntary organisations (either local or national) which support older people or people with sensory impairments. Others had bought, or been helped to buy, their equipment privately or had moved into accommodation (such a supported housing) where certain equipment was supplied as standard. The sections below examine the provision of technology, advice and support and the corresponding assessment of need.

The telecare which 24 participants had in place had in all cases been provided by or through their local authority Adult Services department, although as a consequence of variations in commissioning and charging arrangements, some had to self-fund their use of this service. The installation of a pendant alarm, apart from cases where it had been provided as part of a sheltered housing scheme, typically followed a change in the person's circumstances (as also found in the AKTIVE project). Examples included a person who had begun to demonstrate physical frailty and was considered at risk of falling (or who had fallen), or who was now living alone following bereavement or a change in family circumstances.

In these cases, the participant or a family member or friend had initiated the assessment and installation by contacting the local authority telecare service. Mr Hastings, aged 92, for example, was a widower with severe sight impairment and some hearing difficulties. He had lived alone since the death of his wife and his nearest relatives lived an hour away. He explained that a close friend had experienced a fall at home, spent all night dragging herself to the phone to call for help and subsequently had a pendant alarm installed, persuading Mr Hastings to do the same. He contacted his local telecare service and the alarm was installed the same week.

Accounts differed as to how the pendant alarms worked (a finding also reported in the AKTIVE project); some participants said they had been told at installation that they could not wear their alarm in the shower, for example, which is incorrect. As already mentioned, very few participants had telecare equipment beyond a pendant alarm. Although the study recruitment strategy and size makes generalising about local authority provision inappropriate, other studies have shown that local authority commissioning arrangements can influence the type of telecare products available in a locality (Yeandle 2014).

Mr Houghton, who was 66 and had severe DSI, had the most extensive telecare package in the study (a pendant alarm, smoke and carbon monoxide detectors,

a bogus call alarm and medication reminder, all linked to a monitoring centre). These devices reflected his personal circumstances and needs, as he had in the past been in a house fire, was finding his medication hard to manage and had on one occasion accidentally let an intruder into his home. Although he valued these devices, he felt his local authority had focused on his safety at the expense of his wellbeing, noting that if his home was safe, there was less of a need to help him to go outside, which was what he really wanted to be able to do.

In some cases, local authority Hearing and Vision teams had supplied participants with equipment. Mrs Canning was 67 and had severe hearing and some sight impairment. During the study she 'self-referred' to her local authority's Hearing and Vision team, which sent someone to visit her at home for an assessment. Although she had been assessed three years before and provided with a loop system for her home and an amplifier for her doorbell, she was concerned that her hearing was continuing to deteriorate and felt new equipment might now be available. She was particularly interested in a screenphone. She was frustrated to learn, however, that despite being told she could re-contact the Hearing and Vision team at any time, she was required yet again to complete all the forms she had filled in the first time. She said she was told screenphones were no longer available, and did not feel comfortable with using the relay aspect of a textphone. Three years before, the team had provided a hearing loop system for watching television and listening to music, but Mrs Canning found it too clumsy and awkward to use, as she had to wear a device around her neck; she became '*tangled up*' in the wires and stopped using it. Following her reassessment, a new system was installed around the room. The cost was borne by the local authority, which also advised on a new amplified phone; Mrs Canning was happy with this outcome, and pleased she had been able to instigate the reassessment herself without requiring a referral.

As indicated in relation to Mr Houghton, a few participants were less enthusiastic about their local authority provision. Mr Lane was 68 and had severe DSI. He had contacted his local council twice to ask for a specific DSI assessment. He knew other people with DSI who had had such an assessment, and felt confident he was entitled to one. He explained:

*'I'm coping, and I don't think I need help - and maybe they don't think I need help - but I'd like to log in with them, just in case something happens. I don't want to call in an emergency and not be in the system. I'm managing now, but only if nothing goes wrong'*.

Other study participants had also found obtaining a specialist DSI assessment difficult, and some were unaware this was a possibility. Those who knew they could request a specific DSI assessment sometimes found they were referred to a single-sensory team, or were assessed by someone with expertise in only one type of impairment. Others indicated that assessments had not adequately addressed what they wanted to achieve, and focused solely on risk and safety.

Some equipment, mostly hearing aids and non-electronic magnifiers, had been provided through the NHS. Overall, 32 participants had hearing aids (some purchased privately) and 27 wore them regularly. Two participants had talking blood glucose monitors, although one, Mr Last, aged 74, who had severe DSI, found his hard to use. Although it was designed for someone with visual impairment, he found the buttons hard to distinguish and difficult to navigate using touch. A few people, such as Mrs Bradshaw who was 86 and had severe sight and some hearing impairment, had been referred by the NHS to social services for adaptations and equipment, including the specialist lighting she found essential to enable her to continue preparing her own meals.

In a few cases, people in the study had been supplied with smoke alarms connected to flashing beacons and vibrating alerts through their local fire service, which had visited the groups for sensory impaired people they attended.

Voluntary organisations (especially those which support people with hearing or sight loss or impairment) were a further source of equipment, support and advice relating to technology. Several participants regularly received updates or catalogues from organisations such as the RNIB and Action for Hearing Loss. Others had been visited by local voluntary organisations which advise on technology. Most participants who had received such help were happy with the information they received, although some reported scope for improving this service. Mr Black, for example, who was 64 and had severe DSI, found the technology market hard to navigate. He commented that although voluntary organisations provided advice, no organisations '*dealt with everything*' and some worked only with specific manufacturers.

The equipment voluntary organisations had provided to participants in the study included liquid level indicators, accessible audio players and talking books or newspapers, while Blind Veterans had provided training and higher-cost equipment including electronic magnifiers costing £1,000-£4,000 to some affiliated



participants. Those who voluntary organisations had supplied with equipment on loan particularly valued this option, as some were concerned that changes in their sensory impairment could rapidly render purchased equipment obsolete.

Many participants had purchased some equipment on the private market. Some had met manufacturers and seen the equipment available, before purchasing, at Sight Village exhibitions.<sup>23</sup> Others expressed concerns about using the private market, as they were unsure how to assess the suitability of products or feared a product might become obsolete within a short time. Many felt anxious about purchasing an expensive, but possibly, or potentially, unsuitable product. Even though many manufacturers offered '30-day money-back guarantees', participants still worried '*something better would come along*' soon after they made a purchase, and some were frustrated by their interactions with manufacturers, citing cases where guarantees had not been honoured or equipment had not met the product description.

This chapter has addressed study participants' equipment; the devices they had acquired, and how they came to access them. The next chapter explores how participants used these devices to navigate challenges in their everyday lives related to their DSI.

# Chapter 3 | Sensory Impairment, Ageing and Technology

## Chapter Summary

- *Participants reported the challenges they faced in their everyday lives, some related to ageing more generally and some were specific to their DSI.*
- *The onset of impairment had an impact on coping strategies.*
- *Challenges included managing activities outside the home (including shopping, socialising and travel), inside the home (including cooking and leisure activities) and difficulties in communication and relationships.*
- *Participants provided examples of where assistive technology had helped with some of these challenges.*
- *Technology was not a ‘magic bullet’ that could overcome any challenge.*

Some participants in the study, especially those who were in their 80s and 90s, faced challenges arising from other health conditions and disabilities as well as from their sensory impairments, as indicated in the opening chapter.<sup>24</sup> The team noted differences between those with severe DSI and those with moderate impairment affecting one sense (either vision or hearing) and were also told about the special difficulties of acquiring a second sensory impairment late in life. The research method included conversations about each participant’s biography. These produced data about their sensory impairment trajectory and other events and experiences which helped explain the difficulties and / or successes they had in managing their current situation. This chapter explores three types of example from the study, highlighting these prior circumstances in the cases examined.

## Everyday life for older people with DSI

Some participants reported challenges arising from their sensory impairment which they had overcome, at least partially, using technology; these are indicated in the examples cited, and presented (where appropriate) alongside the case of a second participant of similar age with comparable sensory impairments who was not using technology in the same way. In this way, we indicate the role that technology can play in mediating challenges faced by people with DSI in everyday life.

Our sample included many people who faced some difficulties in everyday life unrelated to their sensory impairment; some had experienced the onset or

exacerbation of debilitating conditions like arthritis or COPD<sup>25</sup> and / or were very frail. Some said they had experienced falls, or feared falling, and were often unsteady when walking. Even without sensory impairment, such conditions limit confidence in managing everyday activities (Fry 2014).

Mrs Dudley was 89 and had for some time been using a wheelchair when she went out. Following an incident while out, in which she had fallen backwards after briefly getting up, she said she now had *'no confidence'* to go anywhere unless she was accompanied, and was considering giving power of attorney to a relative due to difficulty accessing her bank.

Changes in relationships with others also constrained some participants' activities. Many said they were finding some things more difficult but felt reluctant to ask their families or friends for more help, pointing out that they already gave them a lot of assistance or had other demands on their time. Some spoke of wishing to avoid becoming a *'burden'* or *'trouble'* to their friends and families, their reluctance to ask for help sometimes extending to support in using technology. A few participants said family members were unsupportive, despite being asked for help.

Participants with long-standing sensory impairments had often adapted to these and found ways of engaging in their chosen leisure activities. Some did this by involving others who supported them, while others found technology could help. Acquiring additional disabilities or health problems sometimes limited the leisure activities they could now manage. Mr Gill, who had severe sight impairment and some hearing loss, was 74. He had lost his sight in his 20s and until quite recently had been a keen sea fisherman, but had now given up this activity. His wife, who participated in the interviews with him, attributed this to his age rather than to his sensory impairment. Mr Gill now focused on other activities, such as bowls and carpentry, which he had learned to manage with his visual impairment and which were not affected by his other health problems.

Evidence collected from people in the study showed that both the severity of the impairment and the timing of its onset affected how they had adapted to sensory impairment. Its onset in later life could be very difficult, especially if accompanied by other impairments or poor health. For those with a long-standing and severe sensory impairment, loss of (or damage to) a second sense could compromise coping strategies developed earlier in life and many participants found their additional sensory impairment hard to bear.

Mrs Thomas, who had '*struggled*' with sight loss aged 16, describing it as '*a big black hole*', was now 63 and continuing to negotiate challenges with the help of technology. Her recent hearing loss had caused her great concern. She had become less confident about going out independently and worried about becoming housebound. People in such situations tend to rely heavily on their other senses, and if these also become impaired need to develop new approaches to everyday tasks and leisure activities (Brennan & Bally 2007; Scharf et al. 2007). Mrs Thomas was adapting to increasing hearing loss and to new challenges in using the technologies she had come to rely on in managing her visual impairment. She now used bone conduction earphones to go out walking, while simultaneously using hearing aids and a sat nav. At home, she used a refreshable braille display for her tablet device, a hearing loop for her TV and a range of talking equipment. Some of this equipment had helped her to access her local area and participate in different activities in the past, but these items rely heavily on sound and she was concerned that they would become unsuitable as her hearing deteriorated.

Technology could not help with some challenges, and participants who used a guide dog or communication guide stressed this assistance was crucial in retaining their independence. Some participants, however, found a technological device helpful in managing challenges in everyday life. Their positive experiences included using technology to address three types of challenges: challenges outside the home, while travelling, socialising or shopping; challenges inside the home when carrying out routine daily tasks; and challenges related to communication, caring and relationships.

### **Challenges outside the home**

Travel outside the home, whether locally or further afield, presented challenges for many participants. Some were well-travelled and found it hard to adjust to more limited options for holidays. For others, getting out of their homes, even briefly, was not possible without support. This was sometimes due to mobility problems, but in many cases deteriorating sight or hearing affected their confidence, and a few reported a negative experience which now made them reluctant to go out alone.

Those able to go out valued these often brief trips. Others regretted that their lack of support meant they were unable to leave their homes as often as they would like. Mr Last, who was 74 and said he felt like a '*prisoner in [his] own home*', disliked relying on other people to take him out, but felt his DSI made this necessary. He was concerned about his increasing social isolation and often spoke about needing or wanting more social contact so that he could do the things

he liked, such as going for a walk. He had tried a local walking group, but found it *'too fast'* for him, and missed spontaneity, pointing out that whenever he wished to go out, his trip had to be *'arranged'*, and was *'governed by other people'*.

Other participants with quite severe sensory impairment were able to go out alone. Mr Black who had severe DSI and was 64 had been visually impaired since childhood; he went out most days with his guide dog and GPS device with Braille display. Describing the technology primarily as a *'backup'* in case he became lost, he remarked: *'if I want to go, I just go, but I'm nowhere near as brave as I used to be.'* Explaining that he became disorientated more easily now, and sometimes felt giddy, he tended to go to places he knew very well, taking his cane for confidence and his *'very reliable'* guide dog. Box 3.1 contrasts two examples of participants with comparable sensory impairments, one with and one without specialist technology.

### **Box 3.1 Challenges, travel and technology**

#### ***No specialist technology for travel***

Mrs Bennetton is 60 and has severe dual sensory impairment. After a distressing incident in which her guide dog was injured, her confidence when out alone walking is low. Her diary entry read: *'Sadly, I no longer feel safe unless I have another person with me. I never thought I would feel vulnerable and going out alone with my guide dog has become a challenge for me psychologically.'*

She now finds even going to the post box *'exhausting'* and feels her world is getting ever smaller. She feels better when with her communication guide, who gives her the orientating information she needs, but very disorientated when alone.

#### ***Specialist technology for travel***

Mr Greenwood has been registered blind since he was 16. Now 66, he too has a guide dog which has been attacked by another dog when out walking. During the project, Mr Greenwood purchased a new GPS navigator app which initially he described as a *'luxury'*. In later sessions he reported being much more confident using this, and other functions on his smartphone with a Braille display, to access travel information. The GPS app helps if he becomes disorientated and he feels the technology enables him to do *'much more'*. He joked that he needed a *'dog stun gun'*, however, implying that he was still affected by the incident with his guide dog.

Socialising beyond the home was problematic for some participants, especially those with a long-standing single sensory impairment, who found their developing DSI brought new problems as previous management strategies became more difficult. Some participants were concerned about meeting new people and were reluctant to let others know about their DSI. Hearing problems presented some participants with particular challenges in socialising, as they were concerned about communication and about misunderstanding, or being misunderstood by, others.

Mr Black, now 68, had been blind since childhood, and was finding socialising as he would like more difficult as his hearing deteriorated. He felt he could no longer go to the local pub as it was too noisy and he could not be sure he would understand what people said to him. In the past he had attended music clubs and he now also found this difficult. A trial of a personal loop system, on loan from a voluntary organisation, was unsuccessful (it amplified all the sound in the room, making him feel overwhelmed and unwell). Facing such issues, some participants, particularly those unable to leave home unaided, felt quite isolated.

Some people worried about their social relationships in the future. Mrs Canning, who was 69, felt her future would be *'hearing dependent'* and anticipated being lonely due to her communication difficulties. She had considered acquiring a personal loop system but was reluctant to use what she saw as a visible marker of her hearing.

Participants gave mixed feedback on the specialist social groups for older people and people with SSI / DSI which some attended, although some found them very useful and a chance to socialise and access support or advice (including about technology). Others did not enjoy such groups. Mr Suento was 75 and had optic nerve deterioration in both eyes and Charles Bonnet Syndrome. He remarked that they *'reminded him of school'*. Mrs Amis, now 88, had previously enjoyed going to a day club but now felt she would be *'spoiling it'*, as she would need a friend to point out who was talking and to repeat what was being said.

Responding to these difficulties, some participants with increasing DSI changed how they communicated and socialised. In some cases technology took on a greater role as 'email friends' replaced other social contact. Box 3.2 explores these

issues, showing that while technology can reduce some aspects of social isolation in ways some found helpful, it could not truly replace face-to-face interaction.

### **Box 3.2 Challenges, socialising and technology**

#### ***No specialist technology for socialising***

Mrs Canning is 69, has had hearing problems for 25 years and is short-sighted. She says her hearing difficulties are the reason she *'stopped working'* and does not do voluntary work, which she would otherwise like to do. These also trouble her in contexts such as the social events she is regularly invited to attend through her husband's job. She finds her hearing problems embarrassing and is increasingly reluctant to attend these, although she still goes to musical events, saying *'if you miss a few notes, that's not too bad, but if you miss a few words, you lose the plot of a play'*. She feels letting people know she has hearing problems is a *'conversation stopper'*. She knows devices exist to assist with conversations in small groups (such as personal loops) but feels using a loop would signal her disability to everyone. She worries about activating the loop setting on her hearing aids, as it can make them whistle, drawing unwelcome attention to them.

#### ***Specialist technology for socialising***

Mr Houghton is 66 and has severe DSI. He finds it difficult to go out alone, partly due to his DSI but also because he has COPD which made him feel exhausted. He misses social interaction greatly, and values the time he has with his communication guide as this is his main opportunity to leave his home. There are no specialist DSI groups near him, and although he tried the nearest group for visually impaired people, said *'it wasn't for [him] - knitting, nothing for men'*. Mr Houghton has specialist audio software for his PC which enables him to communicate with his *'email friends'*. He goes out only a few times a week, but compensates for this to some extent by using his computer to contact his six email friends, who he met through voluntary organisations. He explained that this is why it is important his computer is working. Although emails and the reader are not perfect, they are the best way for him to keep in touch with people.

Some people in the study were adapting mainstream technology to assist with social interaction. Mrs Crane, aged 83, had been born deaf. Lip reading and sign language had been her main forms of communication until her *retinitis pigmentosa* progressed. Throughout her adult life, she had been heavily involved in local deaf groups. She was very proud of her achievements there, and saw these groups as her main source of social interaction and friendship. With her vision deteriorating at an *'alarming'* rate, she was now struggling to lip read or use sign language and was learning Deafblind Manual which she used to communicate with her family. Mrs Crane said she felt her friends at the deaf club had *'turned their backs on'* her as, despite her efforts, they were finding it hard to communicate with her. She now found it too upsetting to go to these clubs, but had recently become very interested in online Usher forums, where she could view threads using accessibility features on her tablet, and had found videos in BSL. She was now reading the posts and found it reassuring that *'other people are going through the same thing'*.

Like Mr Houghton (Box 3.2), Mrs Crane also had email friends. She explained that when she first felt *'pushed out'* by deaf people she knew, she did not want to talk to anyone and became introverted. She had now become more confident, however; her tablet device had unlocked a new type of social interaction which she had found reassuring during the changes to her sight. This had altered the nature of interactions for her, however, shifting them from outside the home in a group to inside it on her own, as she had not found any equipment that could facilitate communication with her deaf peers.

Outside the home, shopping presented a problem for many participants. Locating what they needed and interacting with staff and other shoppers could be difficult, as shown in other studies of DSI (Brennan et al. 2005; 2006). Some people relied on carers or communication guides to assist them, while others opted to shop online using accessible computer software (which could magnify or *'read'* the screen) and Braille notes or displays. These did not provide the *'social'* aspects of shopping in person, however, which some people missed, and some in the study had made mistakes when ordering from websites which were not laid out accessibly. Online shopping did provide autonomy for some participants, however, as shown in Box 3.3.



### Box 3.3 Challenges, shopping and technology

#### **No specialist technology**

Ms Dumas (67) is partially sighted and hearing impaired. She uses mainstream technology such as her tablet device to shop online, but has some difficulties. She struggles when her eyes are tired and has on occasion mis-ordered when shopping for food and clothing. She prefers shopping online to shopping in person, however, as she is concerned about frustrating other shoppers as she moves slowly around the shop, and at the till because of her visual impairment. Her partner has suggested she could wait for the weekend when he is around so they can shop together. Ms Dumas does not want to do this as she feels if she becomes too dependent on him and fills their leisure time with errands, *'that's a love killer'*.

#### **Specialist technology**

Mr Black (64) has been visually impaired since he was a child and developed hearing problems in the last 15 years. He was *'never a great fan of shopping'* but finds that as his hearing deteriorates, he is less confident about going out with just his guide dog. There are a few shops where he knows people who can help him, but he has started to become disorientated.

Mr Black uses the internet to shop for most things, except clothing, and finds this a satisfactory approach, except when purchasing music, as he misses the *'serendipity'* of finding new things in a shop. He uses a Braille display or note-taker with his PC to shop online.

### Challenges inside the home

During the household visits, the team learned that their sensory impairments presented most participants with challenges within their homes. Cooking, housework, gardening and personal care were among the activities mentioned as more difficult to negotiate with a sensory impairment, quite apart from any other health problems.

Cooking was often difficult because of hazards in preparing food safely. Cutting food could be difficult with limited vision, as could establishing if food had been adequately cooked or was within its 'use-by' date. Technology such as talking scales, microwaves, meat thermometers, one-cup kettles and liquid level indicators could help. Mr Houghton, who was 66 and had severe DSI, had several items of

equipment to help him with preparing food. He had bought some of these, including a talking microwave and a talking meat thermometer, with his Direct Payment.<sup>26</sup> He had no carers, and support from home care staff was limited to twice daily to assist with his personal care. With his technological devices, he could prepare his own meals.

Some participants had arranged for specialist lighting to be installed in their kitchens to assist with preparing food. 'Pen Friend' audio labelling devices could be used to label products and add a use-by date, but many people who had these found them *'fiddly'* to use. Mrs House, who was 86, remarked that it takes a long time to label things, saying *'once you have used a tin of food you have labelled, you need to start again'*. She found the pen reader bulky and instead used her My Reader (a device that magnifies text) to work out what was in various tins, and placed very large labels in her freezer which she could read unaided. Liquid level indicators also received a mixed response. Mr Gill, aged 74, remarked that these were *'more trouble than it's worth'* and relied instead on his own *'asbestos fingers'*.

Those without any assistive technology for cooking tended to be more reliant on others, or had needed to adapt the kinds of foods they ate to those which could be more easily prepared. Mr West, who was 78 and had severe sight and some hearing impairments, commented during one of the household research visits that, *'almost everything is a problem now'*. He was no longer able to cook, due to his visual impairment, and his wife now prepared all his food.

Some people in the sample had technological aids for housework, gardening and personal care. These helped with tasks and activities which participants either continued to manage alone (some noting that their visual impairment made it hard to ascertain whether they were *'doing a good job'*), or with assistance they had arranged. Mr Last, aged 76, said, *'This might sound stupid, but doing housework makes me feel better, helps me feel like I've done something'*. As he was unable to go out alone to exercise, he saw housework as his main form of activity.

Mrs Dudley, who was 89, reported that she was finding getting dressed increasingly difficult. Not only did she worry about the danger of falling while getting dressed, she also found that she sometimes put her clothes on *'back to front'* or *'inside out'*. She was beginning to feel she would need help showering in the future, but said, *'I'm getting to the stage that I'm hating it; I keep putting it off'*.

Some people in the study had items of equipment which helped them with dressing, such as colour readers or mobile apps, including 'Tap Tap See' and 'Be My Eyes', which could help participants identify items of clothing.

In the main, however, participants who had begun to find housework, gardening or personal care difficult had sought practical assistance. This came sometimes from family members or friends, or was organised formally and paid for privately. Several participants with advanced visual impairments noted the importance of keeping their home environment tidy and organised so that they could move around and locate objects. For many, accepting care or help with these tasks was upsetting; something they had resisted to preserve their independence.

Practising their preferred hobbies at home was now challenging for some participants. Reading for pleasure was often mentioned – and might refer to works of fiction, fact or musical scores - but for many it was increasingly challenging because of changes in their sensory impairment. Some used magnifying devices, both electronic and non-electronic, to read shorter pieces of text. Others used Braille displays or specialist software to read documents on their computers. As shown in Table 2.1, talking books and talking newspapers were quite widely used. Some participants with these devices had obtained them from voluntary organisations or local libraries; talking newspapers were posted to them weekly on a memory stick which they then returned the following week. Box 3.4 includes some examples related to reading for leisure. Other hobbies, such as craft activities, were also a challenge for some participants. Some had previously sold the crafts they made for local charities but said they had stopped doing this when their eyesight deteriorated.

### **Box 3.4 Challenges, leisure and technology**

#### ***No specialist leisure technology***

Mrs Walsh (92) has been hearing impaired since childhood and now has macular degeneration, Paget's disease, glaucoma and cataracts. Reading is her favourite hobby, but her sight has deteriorated and she can no longer do this, as the *'letters jump around'*. She now watches TV, but cannot see who the characters are.

#### ***Specialist leisure technology***

Mrs Dudley (92) has Charles Bonnet syndrome and wears hearing aids. As she can no longer read, she uses a device for playing talking books and keeps this beside her end of the settee on a little table. Mrs Dudley said *'[I] love that, absolutely adore it'*. She listens to it every day instead of watching television, which she cannot see well.

Linked to issues in reading were challenges related to personal administration and finances. Participants without equipment to either 'read-aloud' or magnify text often relied on friends or family to read their correspondence to them. This could include personal letters and information about their health conditions. Some pointed out that the more sophisticated devices available for scanning, magnifying or reading correspondence aloud were '*very expensive*'.<sup>27</sup> Mr Last, who was 74, said he would like a scanner but did not feel he could justify the expense. Instead, his sister read him his correspondence, an arrangement he described as '*not ideal*'.

### **Communication, care roles and relationships**

Cross-cutting challenges within and outside the home were issues related to communication and relationships. Problems with communicating and understanding affected many participants as both providers and recipients of care. Some had parents who needed support, while others cared for their grandchildren. Sensory impairment could make both problematic.

Mrs Canning, who was 69, explained that she had difficulty understanding her grandson when she looked after him each week, and Mrs Crane, aged 83, worried that she might accidentally harm her great-grandson because of her sight problems. Both attempted to use their technology to work around these issues. Mrs Canning had a new loop system installed at home through her local authority which she was told would help boost the volume of her grandson's speech; Mrs Crane found that by holding up her tablet device and looking through its camera function she could see her great-grandson more clearly.

Some participants faced difficulties because the person they cared for was reluctant to use technology. Mr Black, aged 64, was trying to provide support to his mother from a distance, but found communicating with her by telephone increasingly difficult as they both had hearing impairments. A keen user of his computer, Braille display and note-taker, Mr Black said his mother was unwilling to use alternatives such as email to communicate. Some others in the study used assistive ICT equipment, including specialist phones and accessibility software for PCs, and found these provided a way of navigating some of their communication difficulties.

Some participants talked to the researchers about challenges in their relationships regarding safety and independence (Box 3.5). Some felt there was a fine balance

to be struck between managing risk and safety and promoting independence, and disagreements about these could sometimes arise between them and those who cared for them. Telecare items, such as pendant alarms, could offer reassurance to participants and those who supported them, and some other items of technology gave participants the confidence to engage in activities which made them feel independent.

### **Box 3.5 Challenges, safety and technology**

#### ***No specialist safety technology***

Mrs Bennetton (60) has severe dual sensory impairment and is concerned about her safety at home. She noted in her diary:

*'I cannot see who comes to the door and feel vulnerable when I open (the) door, as I cannot see or hear well enough. I don't want to say I cannot see or hear the person in case that puts me at more risk. I have had people being verbally abusive or putting their foot in the door, so I cannot close it. So unless I know someone is coming, I mostly don't open door. So I think a door entry system could help, and that is something my husband could install as that is what he used to do.'*

#### ***Specialist safety technology***

Mr Houghton is 66. He explained that, in the past, he had let someone into his home that he *'shouldn't have'*. Fortunately a relative was there and asked them to leave.

Saying that *'you learn from your mistakes'*, he reported that his local authority had installed an intercom, pendant alarm and bogus caller button, all linked to a remote monitoring system.

He now feels safe in his home, and that it is *'secured'*. He still sometimes lets people in without checking the intercom, however, which he admits he *'shouldn't do'*

Mr Last, aged 74, said it was the *'little things'* he had which made him feel more independent. He did not have *'big things'* (such as a scanner to read) but used devices such as a colour reader and a liquid level indicator so that he did not need to rely on others to help him select clothing or make a cup of tea. He explained

that recently, when away from home, he had used his liquid level indicator to make tea for his friends without needing help, which had made him *'feel useful'*.

Options provided, or advocated, by local authorities to promote independence and safety were met with scepticism by some. In addition to the issues of choice versus risk management (explored in Chapter 2), two participants living in different local authority areas said they felt technology was being provided as a way of reducing the need to provide more costly face-to-face contact. While both valued the technology they had, each mentioned that it could not do some of the things they needed, which their communication guides were able to help them with.

This chapter has presented a range of examples of how technology was being used to address these challenges; some participants had difficulties in accessing and using these technologies, however, as discussed next, in Chapter 4.

# Chapter 4 | Barriers to using Technology

## Chapter summary

*Assistive technologies helped some participants address challenges in their everyday lives, but some encountered barriers in accessing assistive technology. Four types of barrier were identified:*

- *Attitudes to technology: some participants' own feelings towards technology made them reluctant to access and use devices.*
- *Information and advice: many participants found obtaining information and advice about assistive technologies difficult.*
- *Cost and choice: the more specialist technology was considered very expensive, and some participants felt constrained in their use of assistive technology by the availability of products.*
- *'Fitness for purpose': some participants said they had obtained technology that had been insufficiently accessible, or had not been delivered in a way which allowed them to access support.*

This chapter discusses the barriers people in the study had encountered in accessing or using telecare and other assistive technology with a communication function. Four types of difficulty were identified through analysis of the data obtained in the research visits; these can be summarised as barriers relating to 'attitudes', 'awareness', 'cost and choice' and the 'fitness for purpose' of available technology and the support and services linked to it.

The first 'hurdle' to overcome in relation to technology was people's own perceptions and attitudes about telecare, assistive technology or technology in general. For some, these meant that from the start they were reluctant or unlikely to access or use such support. Other groups of older people also have concerns, reservations and fears about technology, so this 'attitudinal' barrier is not unique to older people with DSI. The specificity of their concerns is important, however, if they are to be understood and responded to in ways sensitive to their particular, complex and often changeable circumstances.

A second issue was that, even among people in the study with favourable attitudes towards and perceptions about technology, many felt they lacked information about what telecare and other types of assistive equipment existed, what such devices could potentially help them help with, and where they could obtain or access them, or services which could provide them. This lack of awareness, a barrier they share with other older people (AKTIVE Consortium 2013), is particularly important for older

people with DSI, as publicity, campaigns and available information have rarely been developed with their specific needs and circumstances in mind.

The third layer of barriers relates to cost and choice, issues which are inextricably linked. The expense of more specialised equipment affected some participants' ability to access devices of their choice. Even among those who viewed technology positively and were aware of what was available and how to access it, cost was important, as many were using their Attendance Allowance, Direct Payment, Personal Budget or private resources to purchase equipment themselves. Specialist DSI equipment can be expensive, and knowledge about the merits of different options is vital. Some people in the study feared choosing an item which might be unsuitable or which they would find hard to use.

For those who had received equipment through their local authority, the NHS or a voluntary organisation, choice was an issue. Some felt a 'one size fits all' approach was often taken which focused only on risk and safety and did not adequately explore their aspirations.

Even if attitudinal, awareness and cost barriers can be overcome, older people with DSI still face a fourth set of barriers to using technology. This exists when available equipment is not 'fit for purpose' for their specific needs, or when the supporting services, including troubleshooting and aftercare support once equipment had been provided or acquired, were inadequate. This barrier could not be overcome by individuals, however hard they tried to inform themselves or to overcome their anxieties about using something unfamiliar. It arises because in developing, designing and making telecare and assistive technology with a communication function available, insufficient attention has been given to the specific needs, aspirations and difficulties older people with DSI have in managing everyday life. This study's evidence about the everyday experiences of older people with DSI in attempting to find out about, acquire, use and manage such equipment is thus especially important, and forms the main focus of this chapter.

### **Perceptions and attitudes**

Many older people with DSI are sceptical or concerned about using technology and equipment. Reasons for this include personal views about technology in general; past experiences of using technology; and seeing technology as a sign of vulnerability. Resistance to change and to using new or unfamiliar services has been highlighted in previous research as a barrier to use of telecare (Lloyd 2011). In the present study, many people were reluctant to start to use new equipment or incorporate technology into their everyday lives, and some feared coming to depend upon it. Some lacked interest in equipment, or felt they were 'too old' to learn to use it.



## Box 4.1 Overcoming resistance to telecare: Mrs Rodgers

Mrs Rodgers was 88 and had moderate DSI. At the start of the study she explained that her family had been *'nagging'* her to get a pendant alarm. She was hesitant; her past experiences with technology had not been positive, and she described herself as *'not very happy'* about technology. Formerly a clerical worker, she found it frustrating that *'people can just say the computer is down'* as a reason for not providing a service. She had once owned a computer, but gave it up as it was *'taking too much of her time'*. She had a mobile phone, saying 'no one knows the number', which she kept with her in her car and had used only once, to *'call the AA'*. Her son had bought her an electric tin opener which *'did not work'*. These experiences had left her feeling technology was neither useful nor reliable.

Her living situation meant a pendant alarm would be very suitable for her, however: she lived alone, had no home care support, and was concerned about her safety as her house is in a rather remote location, bordering open countryside and woods. She was reluctant to have an exterior key safe as she saw this as a *'sign of vulnerability'*. Giving her key to a neighbour was an alternative, but she did not know her neighbours well and many were *'often away'*. During the interview visits it emerged that Mrs Rodgers was also resisting obtaining telecare support for other reasons: she is very independent, and in past emergencies had managed to summon help without it. When she had a heart attack, she had used her phone to call 999, and when she fell in the garden and broke her ankle she had managed to crawl back into the house to get help.

Despite her misgivings, Mrs Rogers looked into getting a pendant alarm, contacting two local providers (a private company and a charity) but felt both were *'too expensive'* and abandoned the idea. Later, she contacted her local authority telecare service. Finding this more suitable, she arranged a pendant alarm, to *'put my son's mind at rest'*. During the study, Mrs Rodgers was wearing her pendant alarm during the day, but said she had been told not to wear it at night, *'as she could press it accidentally'* and kept it by the bed while sleeping. Describing it as *'nice to have'*, she commented *'in the end they put the key safe at the back of the house'*, explaining that the telecare service held a record of its location.

When the alarm was installed, the installers asked if she had hearing problems, and adjusted the alarm in the telecare unit to ring very loudly when she received a phone call. Initially she did not realise how this would work; she was surprised when her phone rang so loudly and pressed the button to contact the telecare service, which explained this. She finds this *'good'* and could now hear her phone ringing much better than before.

Mrs Dudley, aged 89, who had severe sight and moderate hearing impairments, exemplifies this. Although she was *'interested in'* technology and would like to use devices such as a smartphone to access the internet, she felt uncomfortable with lots of equipment, describing herself as *'frightened'*. She explained that she felt she was born *'too early'*, as a lot of interesting technologies had become available when she was *'too old'* to learn to use them. Similarly Mr Kim, who was 92 and had moderate DSI, described feeling he was *'from a different age. Things that were 'mod' then are old-fashioned now'*.

In describing their resistance to technology, some research participants said they would prefer a person to help them, or to spend time outdoors rather than *'on the computer'*. A few shared the view expressed very directly by Mrs North, who was 85 and had severe DSI, who said, of devices such as telecare, *'the more equipment you have, the more dependent you are. The fewer you have the better'*.

As indicated in previous chapters, some people were living with their DSI and other health problems (see appendix, Table A2, for details). These added further complexity to their everyday lives which also affected their use of equipment and technology. The longitudinal approach used in the study, together with observational data, enabled the research team to identify changes in some participants' health and use of technology.

In the first research visit with Ms Dumas, who was 67 and had severe DSI, she said she was interested in using her tablet computer and in finding accessible solutions to do this. In later visits, however, she said she had not had a chance to progress these plans because of additional health problems and hospital appointments. Several other people in the study had health conditions which made them very tired and which affected their mood, and for them, using technology was not a high priority on which they wanted to focus.

Past experiences with any type of technology seemed to influence participants' use of equipment. Mrs Tysoe, who was 80 and had moderate DSI, lacked confidence in using technology, not because of her DSI, but because of previous bad experiences. She said she was wary of *'breaking'* the computer by *'pressing the wrong button'*.

Past experiences could also help in adjusting to supportive equipment. Mr Hastings, who was 92 and had severe visual and moderate hearing impairment, said he had

*'always been interested in technology'* while Mr Lane, aged 68 and with severe DSI, explained that he had *'always liked technology'*. Both these participants, and some others, mentioned past work experiences in explaining their confidence and competence with equipment.

Some participants feared that using certain devices would act as an outward sign of their impairment. Mrs Canning, also referred to in Chapter 3, was 67 and had severe hearing and moderate visual impairment. She was reluctant to use equipment which might indicate to people that she had a hearing problem, such as a portable loop system. Other people's behaviour and reactions could also create barriers. Mr Glover was 58 and had severe DSI. He had assistive software on his work computer, which read text aloud to him. He had attended courses in using it, but said he felt *'awkward'* using it in the office if others were in the room. Some participants also worried that having certain equipment could cause a security risk, and some had had equipment stolen from them.

### **Awareness of telecare and technology**

The telecare and assistive technology market and the range of available equipment are complex, even for those enthusiastic about using it. Equipment is produced by a wide range of suppliers to address a variety of needs and is typically made available to users or customers through local authorities, the NHS, charities and private sector companies. This complexity was a factor in the limited awareness among older people with DSI of what equipment exists, what it could potentially help with, and how to find reliable information about it, so that decisions could be made about which options to choose from a sometimes confusing array of available equipment.

Several participants were frank about their lack of knowledge. Mrs Fletcher, who was 90 and had severe visual and moderate hearing impairment, simply said: *'I don't know what else is available'*, and Mr Gill, aged 74 and with severe visual and moderate hearing impairment, pointed out that *'it's hard to know what else I would like, technology-wise, without knowing what else is available'*. In other cases, family members and care workers assisting older people in the study said their limited knowledge of what was available left them unable to support the older person with DSI to acquire telecare or other technology.

Not knowing how to find out about available equipment was a further aspect of the 'awareness barrier'. This particularly affected older people in the study who

did not use the Internet or who had no support from voluntary organisations which support older people and / or people with sensory impairments. Some were well acquainted with other types of technology and felt competent using IT, but nevertheless struggled to find suitable information about devices relevant to their specific needs as older people with DSI.

Some of those in touch with voluntary organisations did not realise these provided support with accessing or using technology, but others in the study, especially those with strong links to local or national advocacy groups, had better awareness of equipment and had been supported to use it. Mrs Bradshaw, who was 86, and had severe visual and moderate hearing impairment, regularly attended a group organised by a local voluntary organisation for people with visual impairment. This advised her on equipment, supplied some devices (such as liquid level indicators) and gave her training and support in using assistive and mainstream technologies, computer classes and further help with using her new laptop.

Personal contacts and ‘word-of-mouth’ were an important source of information about technology for some people in the study. Family members sometimes provided support in finding out about technology by searching for information with or for the person with DSI.

Mr Hastings, for example, who was 92 and had severe visual and moderate hearing impairment, explained that if he found any information of possible interest he showed it to his daughter, who researched it further. He had recently come across an article in a magazine for visually impaired people on ‘smart glasses’, for example, and hoped his daughter would be able to find more information. Mr Glover, who had severe DSI and was 58, had a daughter who was also deaf and worked in a hearing impairment charity. Through her work she knew a lot about different equipment, enabling her to advise her father about items and how to access them, and to teach him how to use new things.

Once research participants knew what equipment was available, and how to get it, they faced the next barrier: knowing how to choose the right option. Mr Lane was 68 and had severe DSI. He had helped his stepmother, who also had a hearing impairment, to buy a specialist phone, but said *‘it’s a wild guess as to whether it would work [for her]’*. Mrs Dudley, aged 89, who had severe visual and moderate hearing impairments, was considering buying a new magnifying glass. She said she had been looking for one in a shopping catalogue for people who are blind, but found there were *‘so many options’* she did not know which to choose.

Many people in the study felt an independent advice service would be a valuable source of support in assessing how much to spend. Even participants who described themselves as *'tech-savvy'*, or who had links with voluntary organisations or manufacturers, sometimes felt overwhelmed by the array of available technology. For some, the risk of assessing their own needs and choosing a potentially expensive product was too great, leaving them reluctant to make a purchase, even if they believed an item of equipment might be of benefit.

### **Cost and choice**

Cost acted as a major barrier to access, even for participants who were positive about technology and had an idea of what equipment they would like. Equipment costs vary a great deal, and accessing equipment through local authorities, the NHS, voluntary organisations or private providers had an additional effect on costs and charges. Some people in the study had telecare devices provided through local authorities free of charge, while others found their local authority charged for its telecare service. One person who had paid a £39.99 installation charge for his pendant alarm and was paying £3.99 per week for the service, remarked that this cost *'isn't bad'*; another, living in a different locality, paid £13 per month for a similar service (but no installation charge). He valued the service, which gave him *'peace of mind'*, but said he was reluctant to ask his local authority for a reassessment of his technology (or other) needs as he feared his *'support might be reduced'*.

Some participants had purchased technology from voluntary organisations such as the RNIB or Action on Hearing Loss. They said these organisations offered a wide range of products, but felt they tended to deal with specific manufacturers, making it difficult to compare the full range of products in a particular category. Cost was a big issue for many participants considering a private purchase. The cost of equipment on the private market varied enormously across a wide range of devices. Some were inexpensive (liquid level indicators at around £10) while others were *'big investment'* devices (Braille note-takers, at around £4,700). When asked what equipment they would like, several participants remarked that they were *'lucky they could afford'* to purchase anything they needed. Some used their Disability Living Allowance, Attendance Allowance or Personal Budget to fund their purchases. One person explained that, as he was unable to *'roll over'* more than two months of his Direct Payments, he could not purchase more expensive items, and that he would need *'approval'* for such purchases. He remarked that in these circumstances, his choices were *'not entirely free'*. In another case, Mr Last, who was 74 and had severe DSI, said he was unsure if *'being able to read his own letters'* warranted the £1,500 cost of an audio scanner.

When exploring the option of purchasing technology, many research participants worried that items of equipment would become obsolete as their own conditions changed, or when newer and better equipment became available. Mr Terry, who was 92 and had severe hearing and moderate visual impairment, had a lot of equipment he no longer used. He explained that technology had moved so fast, and things had changed so rapidly, that he *'could not keep up'*. He used his computer regularly, but commented, *'I find technology is moving too fast - the latest phone or Ipad is superseded next week'*, adding that he now felt some items were a *'waste of money'*. Sharing similar concerns, some people wished to trial equipment before purchase to ensure it would be suitable, an option not typically offered.

Cost could also influence participants' ability to access equipment of their own choice. Some, like Mr Last, found equipment they wanted on the private market beyond their means. Those who received equipment and support from their local authority, the NHS or third sector organisations, usually obtained this either free of charge or at a subsidised cost. Commissioning arrangements in these organisations limited their choices, however, and in some cases equipment and support was only available from specified manufacturers. A few participants commented that their local authority provided technology to keep them safe but *'ignored'* their other needs, such as for social interaction outside the home; some felt *'trapped'* inside their now *'safe'* homes.

Mr Black was 64 and had severe DSI. He had initially contacted his local authority's multiple impairment team to arrange an assessment for technology. The team visited and referred him to the hearing team, which Mr Black found somewhat inappropriate as his sight impairment was both more severe than, and predated, his hearing loss. His wife commented that she felt the hearing team assessor had not tried to get a sense of who her *'husband was, what he would like to do or what he was having difficulty with'*. Following the assessment, the local authority installed an infra-red sensor by their gate, linked to a vibrating pager and plastic wrist band. Mrs Black said the *'council have a list, and that's what you get. There are no bespoke options, nothing is matched to the person'*, adding that it might *'cost more and take creativity and time to ensure that what is installed is really appropriate'* for the person. Mr Black found he could not always feel the pager vibrating in his pocket, and disliked the feel of the wristband. There was no follow-up service, so the equipment provided was soon consigned to a cupboard. Mr Black instead purchased a loud doorbell with a portable receiver which he kept with him when moving about the house.

Many other participants had equipment they no longer used, often provided by local authorities, suggesting that better follow-up and reassessment services might significantly reduce the waste involved when technology is supplied but not used. Others found it challenging to arrange the installation of even a simple telecare device. One case (Box 4.2) is of particular interest as it indicates that even someone with determination, knowledge and skills can find obtaining suitable equipment at the best price challenging and confusing, and be misled by inaccurate information.

#### **Box 4.2 Telecare and cost: Ms Jackson**

Ms Jackson is 72, divorced and lives alone with her dog. She has moderate hearing loss (and uses two hearing aids), is long-sighted and has mobility problems arising from a motor accident several years ago. When the study began she had a pull cord, provided by her housing association, mainstream equipment purchased privately (laptop, tablet device, mobile phone) and mobility equipment (mobility scooter, raised toilet seat and grab rails).

Ms Jackson is an example of someone navigating through the barriers of unawareness and access to equipment. She volunteers in hearing impairment and pensioner groups, has good awareness of her rights and is used to making things happen. Following changes in her health, she sold her house

and moved to supported housing. She had used her own funds to modify her bungalow and purchase safety and leisure technology and mobility aids to ensure she is well prepared for ageing and living with DSI, now and in the future with possibly poorer health. Prior to a hip operation she wanted to arrange a pendant alarm, but was told her housing association no longer provided these, so arranged a pendant through a local charity, which cost more than she expected. Around this time she wrote to her housing scheme manager about a separate matter, mentioning her disappointment at having to source her pendant alarm elsewhere. She learned that in fact the housing association still provided pendant alarms, managed to change providers and secured a cheaper option.

As indicated in Chapter 2, attempting to obtain equipment through local authority Adult Services departments had been problematic for some in the study. Mr Hopkirk was 99, had severe hearing and moderate visual impairment, and lived with his wife, saying they were both *'housebound'* and reliant on services *'coming to them'*.

He felt his local audiology service had *'given up'* on him, and worried that he was not being referred for potentially helpful equipment. Others in the study received help through their local authority but felt worried about contacting them again, even when their needs changed, saying local services were being cut back and that they feared having a reassessment might lead to the loss of the support they already had.

### **Fit for purpose?**

The barriers older people with DSI encountered with the equipment they used arose from both general and DSI-specific usability issues. As equipment often did not fully meet their needs, some people in the study had needed to compromise, particularly when their DSI or other health conditions changed or new technology became available. This, and issues of trust in the equipment and in organisations delivering the service, are discussed next.

For many research participants, the technology and equipment they could access was *'a compromise'*, which did not fully meet their needs (Box 4.3). Liquid level indicators, for example, are devices used when pouring liquid, such as tea, into a cup to indicate when it is full. They are often given to older people with visual impairment by local authority services, and eight people in the study had them. Several explained that they did not use their indicator; Mrs Brady, who was 90 and had severe DSI, explained that her main problem was being able to know where the cup is, so that she can pour liquid into the cup. She had stopped using her liquid level indicator and now only had tea when a family member was present to make it.

Many older people with DSI have conditions which are changing, a situation which necessarily affects their use of technology. Mrs Crane was 83 and had severe DSI. Her sight changed significantly during her participation in the study and the equipment which was helping her when it began ceased to be of any use. By the second research visit, she could no longer tolerate bright lights, whereas in the initial visit she needed to have a spotlight directly on what she was looking at. In addition, she could no longer see the flashing light of the beacon linked to her doorbell.

Another participant found his circumstances were incompatible with otherwise useful equipment. Mr Lane was 68, had severe DSI, lived alone and had a guide dog. He and his daughter were keen to find equipment to support him, and



discussed items with sensors, designed to detect if there is no movement in a home or particular room, and to raise an alarm as this could indicate the occupant has had an accident. They considered installing such equipment but feared it would not work as his guide dog might trigger the sensors.

### **Box 4.3 Limitations of equipment and services: Mr Gill**

Mr Gill is 74, has severe visual and moderate hearing impairment, and has talking newspapers, a talking computer, a mobile phone for visually impaired people and a talking watch. He also has a liquid level indicator, although he does not use this, saying it *'is more trouble than it's worth'* and preferring to rely on his *'asbestos fingers'*. Faced with other difficulties in using equipment, Mr Gill feels his background in engineering gives him the confidence and skills to modify things. He feels equipment is often designed for low vision, however, which is of no use to someone with no vision.

Mr Gill said he cannot use touch screen devices as he has no vision at all, and Braille readers linked to these devices do not work for him as he has largely *'forgotten'* Braille, saying it's not *'useful enough to keep'*. None of his friends use Braille to communicate, and it takes him a long time to read anything. Although Mr Gill has the skills and interest to modify equipment to meet his needs, the design of some equipment is a barrier he cannot overcome.

Another barrier in using telecare and other supportive equipment relates to the suitability of equipment for people with severe visual impairment. Mr Bailey was 88, had severe visual and moderate hearing impairments, and lived in supported housing. He and his care worker explained that his visual impairment was a significant barrier to his use of equipment. He had a mobile phone which he could answer if someone called, but could not use it to make calls, because of the complexity of the phone and his sight impairment. His care worker explained that she had put 'blu-tack' on the buttons to help Mr Bailey know which to press. He also had pull cords in his apartment, but did not know where they were.

Many participants commented that a lot of equipment was designed for people with at least some sight, or was designed for people with sight problems but who depended on hearing. Mr Small, who was 82 and had severe DSI, had various items of DSI-specific equipment. His computer had speech-to-text software which is designed to learn from mistakes. This only works if errors are corrected at the time, however, and Mr Small cannot do this as he is unable to see what is typed

on the screen. His way of checking text was to print it out and then use his video magnifier or scanner to read it. This left him able to use only limited features of the equipment. He explained that the software was also problematic for a visually impaired person, as it had a sidebar with extra information which his screen reader did not pick up, remarking, *'it has been designed by a sighted person for a sighted person'*.

As well as limited vision, many older adults with DSI have limited manual dexterity which affects their use of equipment. Mrs Dudley was 89, had severe sight and moderate hearing impairments, and a telephone with large buttons. She could see these buttons but was not always able to press the correct ones.

Poor experiences also affected how people used the equipment. Mrs Sayers was 99 and had severe DSI. She had experienced false alarms with telecare equipment, affecting both her pendant alarm and her fire alarm. During the third research visit she said she was *'fed up with the pendant alarm'* and was now keeping it in her pocket rather than wearing it around her neck as she had done previously.

Many research participants felt they had lacked necessary guidance on using the equipment they had acquired when it was initially installed or obtained, needed ongoing support which was not available, and that review or reassessment for suitability was lacking (Box 4.4). Many mentioned having limited support when equipment was provided. Unable to see the equipment they are trying to learn how to use or to read the instruction manuals and guidance which came with it added to the more general problems any older person might have with new equipment.

This section considers the types of help and support research participants had looked for or received, including formal support such as courses or one-to-one assistance and ongoing support from organisations and charities.

Learning to use new technology brings challenges for anyone, but participants in this study faced significant additional barriers. As already noted, some felt they were *'too old'* to learn to use something new, and some encountered problems learning to use their new equipment. Mr Lane, aged 68, who had severe DSI, said he needed to read or listen to *'anything'* several times before he gets all the information he needs; for him, learning to use new technology was very difficult unless it was intuitive enough to learn through usage.

#### Box 4.4 Support with equipment: Mr Small

Mr Small lived in retirement housing, had an interest in technology through his past career, and was active in looking for support and equipment that might help him. Aged 82, with severe DSI, he actively accesses support from both local and national groups. Despite this, he has encountered various challenges in obtaining equipment, getting it to work, and with support. He wanted to buy a smartphone to use voice recognition with calls and sending texts, and during the study visited a visual impairment technology support group to review different options. He then bought a phone, with a tactile grid for easier use, but struggled to get the phone to work. The instructions came on a CD, not on paper, in a format not compatible with his accessible software. He tried to access support via a charity for people with visual impairment by phone, but *'got too muddled to make it work'*. The charity then organised a volunteer to visit him to help with his smartphone, but as the volunteer had no experience with this type of phone it took a long time to get it working for him.

This was not his only experience of problems with new equipment and accessing support to make it work. His local authority's sensory impairment team had provided him with a hearing loop for his stereo after complaints from his neighbours about loud music. This was installed, but Mr Small lacked sufficient information about how it works, so could not hear the radio well. He complained about this and eventually took it with him to a hospital appointment in the audiology department. Staff there showed him how to turn the volume up and this equipment now works well.

In both these cases, and despite Mr Small's skills and understanding of technology and access to support, the initial lack of follow-up and one-to-one support from the equipment provider meant he was unable for some time to use the equipment to its full potential.

Mr Small was among a small number of research participants who had received support with his visual impairment from Blind Veterans. Through this organisation, he had attended courses, taken holidays and received equipment on permanent loan. He had previously looked into video magnifiers and found they were very expensive. He contacted Blind Veterans in his search for information and was offered a video magnifier on permanent loan. When the magnifier did not work well for him, Blind Veterans took the equipment away and fixed it. He was delighted with this support, explaining that he now used it *'pretty well for everything'*.

Many people said their key source of support in relation to technology and equipment was informal help from family or friends, some of whom had previous knowledge of specialist or mainstream technology and were active in looking for solutions. Mrs Sayers, for example, who was 99 and had severe DSI, had difficulties with her television and a computer, and was helped by her granddaughter to use these. She nevertheless found it frustrating that her granddaughter fixed things ‘*so quickly*’ that she was unable to learn how to do them herself, and was finding it increasingly difficult to see the computer screen. In other cases, the older person needed more support but found family members resisting this rather than helping, perhaps, they thought, because of the stress or anxiety they were also feeling.

Some research participants received help through courses and organisations, although for some older people with DSI this was of limited value. In the setting of a training course, their communication problems could not always be addressed, and some said they would have preferred one-to-one support, as their need for tailored, individualised support was not accommodated. Mrs Thomas was 63 and had severe visual and moderate hearing impairment. She was an active user of technology and had learned to use many items independently, but explained that she would value bespoke support to choose equipment based on her individual needs. Mr Suento was less confident about learning to use a new item. Aged 75, with severe visual and moderate hearing impairment, he was not interested in attending classes or courses to learn about assistive technology, but said he would have used one-to-one support had it been offered or available.

This chapter has presented the key challenges reported by participants in accessing and using technology. As reported in Chapter 3, certain devices in some contexts could make a real difference and assist a person with DSI in negotiating challenges inside and outside their homes and in communicating with others; however, accessing and using those devices was not unproblematic, and depended on attitudes, awareness, costs and equipment design.

# Chapter 5 | Conclusions and Recommendations

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## Conclusions Based on the Study

The study reported here was commissioned by Sense in 2014 to address research questions about the types of telecare equipment or other assistive technologies available to older people with DSI; about the agencies and providers which offer, arrange and monitor this support and the scope for widening access to it; about the constraints in the everyday lives of older people with DSI, and how telecare and technology might assist them in managing these; and about barriers to the use of technology by this group of older people, recognising other health conditions they might also have.

The context for the study, indicated in Chapter 1, demonstrates both the need for detailed research into the needs and aspirations of older people with DSI, remarkably absent in the wider literature on telecare, assistive technology and older people, and the urgent need to learn from, and to apply, the insights it yields.

Older people with DSI are a fast-growing group which includes many people who, even at advanced ages, are trying to live meaningful lives as independently as possible, applying much skill, determination, resourcefulness and creativity in doing this. With their numbers likely to be well over 400,000 in just 15 years' time, it is evident that service providers (whether in the public, voluntary or private sectors), equipment suppliers and product developers all have much to do to ensure support exists which can meet their diverse needs.

In the decades ahead, the array of available equipment, already bewilderingly complex, is likely to become even more varied and to include new and more sophisticated devices designed to help people with DSI overcome some of the difficulties they face. Based on information collected from the 38 participants in this research, five different types of equipment were identified, within the broader concept 'telecare and assistive technology with a communication function' used in recruiting them to the study.

The five-fold typology, set out in Chapter 2, comprises 'Alerting' and 'Assistive Listening' technologies, 'Visual Impairment Equipment', 'Specialist Equipment for

using ICT' and 'Assistive Telecommunication Devices'. It differs a little from previous categorisations, as indicated in Table 2.1. As detailed there, many specific items of equipment were used, or had been acquired, by few people, so across all 38 participants, the range of items was relatively large. The observations, interviews and other techniques used in the repeat 'Everyday Life Analysis' visits to people in the study revealed in detail how these items were acquired and used in supporting them in their homes, as they undertook daily household tasks, engaged in activities outside the home and communicated and interacted with others.

The study also analysed the barriers which impede older people with DSI in fully benefitting from the telecare and technology products and devices theoretically available to assist them. These could start with 'attitudinal' barriers; often a fear of, or reluctance to try, something new. For some, this was based on prior unsuccessful experience with equipment or technology, or was linked to a perception that, for someone in their situation, with impairments affecting both vision and hearing (and in some cases other difficulties), most equipment would be either very difficult to use (or learn to use), or completely inaccessible.

Many people in the study spoke of their difficulties in everyday life; in getting dressed, preparing meals, keeping their homes clean and tidy, shopping for food and essentials and participating in valued hobbies, social interactions and other activities. Their accounts showed that many faced these difficulties, while coping with severe and sometimes deteriorating impairments to their vision and hearing, with fortitude and creativity. Negative attitudes towards technology were a factor for some people, but were not the main impediment to effective use of technology for most of the 38 older people with DSI who took part 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, however, sometimes shared also by those who supported or who were trying to assist them. Carers, home care workers and even some of the professional advisers they encountered often had limited knowledge of what existed, what would help, how to get it, and, in particular, what might be the best combination or configuration of equipment to make their everyday lives a little easier and facilitate the activities and interactions they wished to maintain.

In the study, equipment had been obtained variously through local authorities (sometimes through their Hearing and Vision teams, in other cases via their telecare

service); NHS providers, both via hospital services and primary care; voluntary organisations, including those specialising in support for people with sensory impairment and older people; other statutory services, including fire services; and via private purchase. For the latter, online sources were an important, although not the only, means of locating information, placing orders and arranging services and supply.

The cost of equipment, charging arrangements and loan options were further barriers, and something of a mystery to many. Local authority charging policies, for example for telecare, vary and can be quite different even in neighbouring authorities. In addition, supply of other technology and equipment is discretionary for local authorities, in terms of the service and equipment offered, whether or not these are chargeable and, where applicable, the prices set (installation, product, service and replacement charges all vary).

On the private market, the more sophisticated items suitable for people with DSI can cost thousands of pounds, so acquiring these involved both making important decisions and having adequate resources. Some in the study felt they were fortunate in being able to purchase items privately, but many had limited resources; some used their Direct Payment, Personal Budget, or Attendance Allowance to finance these.

Many people spoke of the need for accessible, reliable and disinterested advice in selecting equipment for purchase; most said this was very hard to find. Some specialist charities had offered much-appreciated guidance, in some cases facilitating the loan of costly equipment, but most lacked the advice they needed to select a suitable item, learn how to use it, troubleshoot any difficulties, and decide when to replace it.

Obtaining an item which was not quite what was needed, which was hard to learn how to use, or did not work well with other equipment, was a common experience. Many spoke of experiencing frustration and disappointment with items they had acquired or been given. Further, the equipment provided was often designed for a person with hearing impairment (so relied on vision) or for people who were blind or visually impaired (and so used sound or required good hearing). Few items of equipment seemed to have been designed for those with DSI, and few designers or product developers appeared to appreciate that, especially for older people, DSI is often accompanied by difficulties with manual dexterity, balance,

mobility and stability, and that product design needs to reflect this. Designers and manufacturers should perhaps be encouraged to make products accessible to the widest possible market, including people with DSI, rather than to view people with DSI as a niche market, for whom 'add-on' product modifications are required.

There were, nevertheless, some important 'success stories' in the study, including people who, with suitable equipment and technology in place, felt much safer in their homes, were able to travel and use public transport alone, could manage everyday chores and pleasures unaided, and had found new modes of communicating with others which at least partly offset the disappointment and sadness they felt as face-to-face interaction, especially in groups or noisy environments, became increasingly difficult and frustrating. The study included people delighted to have 'email friends' with whom they could communicate, pleased to be able to make tea or a meal not only for themselves but also for others, and happily enjoying reading and managing their personal affairs as they now had equipment which enabled them to do this.

The many benefits of acquiring technology which suits the abilities of an older person with DSI, compensates for things they cannot do, is relevant to their needs and aspirations, and is affordable within their budget, are self-evident from the examples cited in the report. The report's recommendations therefore focus on how these could be extended to more of the hundreds of thousands of older people with DSI who could benefit from the following:

- knowing more about available technology and equipment;
- simpler pathways or a single point of access, not a complex mix of suppliers and providers;
- ready access to disinterested and up-to-date support and advice;
- opportunities to trial equipment and, where possible, obtain it on loan;
- access to equipment and product ranges designed with an older person with DSI in mind;
- one-to-one support in learning how to use new equipment and troubleshoot problems; and
- a seamless service, tailored to the needs of older people with DSI, from enquiry, through assessment of need, installation, aftercare, troubleshooting and product replacement (when needs change, or improved equipment becomes available).



The recommendations made below focus on different ‘actors’ in the wider system in which achieving these goals would need to be embedded: Sense, as the leading charity for deafblind people, and other voluntary organisations offering older people with DSI support; local authorities and statutory service providers who have legal obligations which affect services for older people with DSI; technology manufacturers and designers, who create and make products within the five-fold typology of telecare and assistive technology identified in this report; older people and those involved in supporting them, including their families, carers, communication guides and home care staff; and health professionals, whose detailed knowledge and understanding of the different conditions older people with DSI may have is vital in ensuring the technology provided addresses both their current situation and how it can be expected to develop.

As all participants in this study lived in England, the wider system here is taken to be the English system of health, social care, emergency and local services; the legal framework of law which shapes these; and the particular configuration of state, voluntary and private sector support which now exists in England. The report is especially timely, as a new focus on Technology-Enabled Care Services (TECS) was adopted in 2014 (NHS Commissioning Assembly 2015). Many of the recommendations would, however, be readily adaptable to other national contexts.

### **Limitations of the study**

The study reported here was small scale, and designed within the constraints of a modest budget and tight time-frame. There is no available sampling frame from which older people with DSI can be identified and recruited into a study, so recruitment methods relied on Sense and other agencies already in touch with people in this group, and included use of ‘snowballing’. The study cannot claim to be representative of all older people with DSI living in England. Its findings are based on the experiences, views and accounts of the 38 people who took part; and details of the accounts they gave could not be checked with other sources. Recruiting through Sense and other specialist agencies means older people with DSI not in touch with these groups did not participate in the study. Many older people with SSI or DSI cope without support from statutory or voluntary services (as noted in Chapter 1); their impairments are often viewed as a normal aspect of ageing (Scharf et al. 2007) and some claim statutory guidance on supporting people with DSI lacks clarity (Hodges and Douglas 2007).<sup>28</sup>

The study included a longitudinal dimension, considered an essential aspect of the chosen design. This was quite short, however, and the study could not assess longer-term consequences of participants' use of technology or identify how well or badly they might fare in the longer term.

Everyone who took part in the study had some technology in place, so the research findings are based on people likely to be more positive about technology than the wider group of older people with DSI. As they were already in touch with support they were probably better informed and supported than others who were not. People who fear, dislike or find it difficult to accept technology as an element in their support are likely to be entirely missing from the study.

### **Issues for future research**

New studies of this growing group of people are urgently required, as their needs, experiences, preferences and circumstances have been under-researched for far too long. Qualitative methods should form part of any study of this group because of their complex circumstances and the challenges they face in communicating their perspective using mainstream channels (e.g. responding to fixed-response questionnaires).

However future studies should ideally be larger-scale, should explore the situation of older people with DSI without as well as with technology in place, and should include a group introduced to technology during the study period, to enable their experiences of using these to be examined from the start of their experience of researching, accessing, acquiring and using technology. Studies are also needed of agencies working with older people with DSI, and of the design and R&D processes used in developing new technology to address their needs, to understand weaknesses in existing arrangements and the issues faced by professionals and practitioners in providing more effective solutions and support.

## 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.
- Adding **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.

# Endnotes

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<sup>1</sup>AKTIVE was an academic-industry project, funded by the TSB (now known as Innovate UK) with co-funding from industrial partners. The AKTIVE social research team comprised staff at the Universities of Leeds and Oxford, led by Sue Yeandle with the support of a multidisciplinary consortium. For details, see: [www.aktive.org.uk](http://www.aktive.org.uk).

<sup>2</sup>Telecare is defined here as: *'equipment and detectors that provide continuous, automatic and remote monitoring of care needs emergencies and lifestyle changes, using information and communication technology (ICT) to trigger human responses, or shut down equipment to prevent hazards'* (Scottish Government, 2009).

<sup>3</sup>Age-related changes to sight include presbyopia; increased light transmission of ocular media and decreased pupil size; loss of contrast sensitivity and greater sensitivity to glare; delayed recovery from glare and darkness; and reduced visual field and colour discrimination. There are also pathological conditions related to age (macular degeneration, diabetic retinopathy, cataract, and glaucoma) and other conditions which increase the risk of visual impairment (multiple sclerosis; stroke; malignant hypertension).Hearing impairment is more likely as people age due to changes to the inner ear and the central auditory system; long-term exposure to noise also affects hearing (Saunders & Echt 2007).

<sup>4</sup>Statutory guidance issued in 2001 (DoH 2001) requires local authorities to record the numbers of people they have identified as having DSI, but Hodges and Douglas (2007) argue there is no common understanding of how to apply the definition.

<sup>5</sup>Katz (1983).identified the 'Instrumental Activities of Daily Living' as housework, taking medicines, managing money, shopping, using phones or other forms of communication; and using technology or transport.

<sup>6</sup>Three databases were searched: Medline, searched by article title and abstract; Scopus, searched by title, keywords and abstract; and Google Scholar, searched by title only.

<sup>7</sup>Not all articles featuring the search terms selected were relevant; for example some focused on younger people or on professionals' training needs.

<sup>8</sup>Papers which were conference proceedings or which did not relate to older people were excluded; any duplicates were also excluded from this total.

<sup>9</sup><https://www.sense.org.uk/content/technology>.

<sup>10</sup>Touchscreens can present new problems for people with some types of impairment.

<sup>11</sup>E.g. Eyesfree, a navigation app for people with VI which identifies obstacles / provides location context; and SoundAMP which can amplify speech with a 30-second replay button (Doughty 2011).

<sup>12</sup>With Tap Tap See / Be My Eyes, people with VI can identify objects with a smartphone camera.

<sup>13</sup>As the study progressed, it proved impossible, for a variety of reasons, to retain all participants in the study across all four planned household visits. The team included in the final analysis of the research data those who participated in the study over at least two visits.

<sup>14</sup>Technical aspects of the methodology are described in more detail elsewhere (Yeandle et al., 2014).

<sup>15</sup>The topic guides are included in Appendices A3-7. Available online from authors on request.

<sup>16</sup>All 38 participants were given pseudonyms, which are used in this report. In some cases, other potentially identifying details have also been changed.

<sup>17</sup>This person came into contact with the project through his role in the DSI community. The research team included him in the project (although he did not quite meet the age inclusion criteria) as they hoped he would be helpful in finding other participants (through snowballing). In his case, the focus of the visits was adjusted to explore his future aspirations and preparation for older age.

<sup>18</sup>PIS is 'Passive infrared sensor'.

<sup>19</sup>In this categorisation, we did not include mainstream technology such as smart

phones and tablet devices unless they had a specialist programme installed. Some participants had such items and enabled their in-built accessibility functions. For some, the touch screens of smart phones and tablets did not offer the tactile cues they relied upon. This means that as these devices come into more widespread use, there is a risk they will be inappropriate for some people with DSI. Touchscreens or 'soft touch' buttons were a concern for participants in other contexts too, for example in washing machines, microwaves and ovens, which thereby became less accessible. Mr Gill had several '*old fashioned*' microwaves with dials and buttons which enabled him to feel the settings as '*back-ups*'.

<sup>20</sup>Three people had a smoke sensor linked to a 24/7 telecare monitoring centre or the fire service (including one with a carbon monoxide detector, medication reminder and bogus caller alarm).

<sup>21</sup>Desktop scanners / electronic magnifiers currently range in price from £1,000 to about £4,000.

<sup>22</sup>Braille note-takers range in price from £2,500-£4,800; Braille displays from £1,000-2,800. Few participants read Braille, so cost alone did not explain the low occurrence in the sample.

<sup>23</sup>Sight Villages are exhibitions of assistive technology, organised by Queen Alexandra College, held around the UK: <http://www.qac.ac.uk/exhibitions.htm>.

<sup>24</sup>The other conditions they reported were noted in Chapter 1 and are detailed in Document A2 in the appendix to this report.

<sup>25</sup>COPD is 'Chronic Obstructive Pulmonary Disease'.

<sup>26</sup>Direct Payments are payments from a local council to a person who has been assessed as needing help, and who would like to arrange and pay for their own care and support services. Payments are made directly to the disabled person (or to someone acting on their behalf) to arrange their own care package.

<sup>27</sup>These devices range in price from £1,000 to £4,000.

<sup>28</sup>The Department of Health issued revised guidance in 2009 which aimed to respond to this point (DoH, 2009).

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