

# The AT Information Network

## Mapping the Information Environment, the Challenges and Opportunities

2<sup>nd</sup> Year report on activity and findings arising from Years One and Two:  
April 2008-March 2010



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## 1 The Assistive Technology (AT) Alliance project

Four leading national charities that provide impartial information about assistive technology (Assist UK, Disabled Living Foundation (DLF), the Foundation for Assistive Technology (FAST) and Ricability) came together in 2007 to form the Assistive Technology (AT) Alliance. The aim of the AT Alliance is to effect positive change in the market for assistive technology through information provision. There is a secondary aim to consider the potential benefits of closer collaboration for each organisation.

- Assist UK leads a UK wide network of locally-based Disabled Living Centres. Each centre includes a permanent exhibition of products where people can try a variety of assistive technology solutions and get impartial and free advice from professional staff and disabled people ([www.assist-uk.org](http://www.assist-uk.org)).
- The Disabled Living Foundation (DLF) provides information, advice and training to support independent living and choice for those who need assistive technology. Its services include a database of equipment called DLF Data, a national Helpline, free factsheets, one of the largest equipment demonstration centres in the country and a number of online services, including a guided advice tool AskSARA and a free-to-use advice website on daily living equipment, 'Living made easy' ([www.dlf.org.uk](http://www.dlf.org.uk), [www.dlf-data.org.uk](http://www.dlf-data.org.uk), [www.asksara.org.uk](http://www.asksara.org.uk) and [www.livingmadeeasy.org.uk](http://www.livingmadeeasy.org.uk)).
- The Foundation for Assistive Technology (FAST) works with organisations across the AT community in statutory, voluntary and private sectors to advance innovation in product design, to encourage the adoption of technology by disabled and older people and to support AT service improvement ([www.fastuk.org](http://www.fastuk.org)).
- Ricability is a national independent consumer research charity that produces free, practical information for older and disabled people. It carries out a range of research, product testing and evaluation, mystery shopping, and information and helpline evaluation. Ricability produces consumer reports, engages people in consumer testing and engages in consultancy to support organisations to provide accessible information about AT for disabled and older people ([www.ricability.org.uk](http://www.ricability.org.uk)). The organisation also has websites for specific product information and reviews ([www.ricability-digitaltv.org.uk](http://www.ricability-digitaltv.org.uk) and [www.product-reviews.org.uk](http://www.product-reviews.org.uk)).

In April 2008 the AT Alliance received three years' funding from the Department of Health for a project entitled "The Assistive Technology Information Network for the Future". The project's aim is to bring together the organisations' expertise on information, evaluation, policy and user experience relating to assistive technology. The work of the project is set against the changing market for assistive technology and an anticipated increase in information-seeking by the public. Bringing together the experience and expertise of these four organisations and developing stronger collaborative working will provide a platform to address gaps in access, information and choice. This report summarises the work and learning of the first two years of the project.

## 1.1 Definitions of assistive technology and scope of the project

### 1.1.1 UK definition of Assistive Technology

There are a number of definitions of Assistive Technology. For the purpose of the project it was agreed that the following definition will be used:

***Assistive Technology (AT) is any product or service designed to enable independence for disabled and older people.***

This definition was agreed at a King's Fund consultation meeting in March 2001 to find a term to replace 'disability equipment'. This umbrella term is widely used by professionals, academics and researchers in the UK because it more accurately reflects the broad range of equipment and services that assist older and disabled people of all ages to maximise their independence. It acknowledges the cross over between inclusively designed, adapted and mainstream products and the technology specifically made available to assist disabled and older people. However, as a term it is not yet well-known by the general public.

The key advantage of this definition is that the characteristic outcome is 'independence' in contrast to other definitions that set functionality and safety as outcomes. As it was strongly influenced by disabled and older people, it is unsurprising that this definition is in line with the disability movement's support for the personalisation of services. It implies an evaluation of assistive technology services through the measurement, in part at least, of personally-set outcomes.

#### **Alternative definitions**

Given the context of service provision and evaluation within statutory services in the UK it is to be expected that researchers and practitioners often feel comfortable working with a tighter definition that relates more closely to outcomes relevant to comparable health interventions.

- One good definition that achieves this without circumscribing outcomes too closely is this one by Cowan and Turner-Smith<sup>1</sup> that describes assistive technology as 'Any device or system that allows an individual to perform a task that they would otherwise be unable to do, or increases the ease and safety with which the task can be performed'.
- Similarly the World Health Organisation<sup>2</sup> has defined assistive technology as 'An umbrella term for any device or system that allows individuals to perform tasks they would otherwise be unable to do or increases the ease and safety with which tasks can be performed.'
- The United States is the only country in the world with statutory legislation relating to the acquisition of assistive technology and a definition of assistive technology with legal standing. The US Assistive Technology Act<sup>3</sup>, provides the following definition of an assistive technology device. 'The term 'assistive technology device' means any item, piece of equipment, or product system, whether acquired commercially, modified, or customised, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities.'

Learning from the United States was that to define the term too closely using illustrative lists of equipment runs the risk that any associated legislation, funding or regulatory measures failed to cover emerging technologies not included in the listing.

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<sup>1</sup> The Role of Assistive Technology in Alternative Models of Care for Older People by Dr. Donna Cowan and Dr. Alan Turner-Smith, 1999

<sup>2</sup> World Health Organisation "Glossary Of Terms For Community Health Care And Services For Older Persons", 2004

<sup>3</sup> The Assistive Technology Act of 1998 [105-394, S.2432], US Government

## Alternative uses within the UK

Assistive Technology (AT) is still used to denote a particular sub-range of equipment by different sectors; for example, people working in the education sector tend to define AT as products and services which assist learning: access to computers, both hardware and software, communication aids and digital learning aids. Additionally, there has been mention of 'Assistive Technology' within government policy denoting only telecare and telehealth applications. As integration across services to disabled and older people increasingly takes place between health, social care, education, housing and employment services such variation in the use of the term will resolve itself.

### 1.2 Use of the term 'assistive technology' by AT Alliance members

There are good reasons not to use the term assistive technology in formats aimed at public audiences. Due to low awareness of the term most people do not use it to initiate their search for information<sup>4</sup> but instead use everyday terms for specific products or product ranges. In this sense the umbrella term 'assistive technology' is not always the most useful to help people find a specific solution; in addition, some research by Tinker et al suggests that older people find the term off-putting<sup>5</sup>.

In order to respond to people's search requirements it is therefore appropriate to use terms that are related to the clusters of technologies sitting under the umbrella term of assistive technology e.g. mobility equipment, stairlifts, etc. or generic terms such as gadgets, kit, equipment, etc.

However, in responding to the search terms used by the public, who are unaware of the broad range of equipment that may provide a solution to the challenge they are attempting to address, there is the potential of missing an opportunity to raise awareness of these solutions. In other words, people don't know what they don't know. There is also a case to be made for raising public awareness of the term in an appropriate context, which is as a useful umbrella term, indispensable for planning, etc. An analogy here is the use of the term 'transport'. Members of the public do not on the whole say 'I'm just going to catch my transport into town' but say 'the bus' or 'the number seven'. However, for transport planners and when talking about issues relevant across different forms of transport it is a useful umbrella term.

Following a review of the use of the term 'assistive technology' on Alliance members' websites it became apparent that although it featured heavily in FAST's website which deals with policy and strategic planning, in the more public facing websites of other Alliance members it is not used as frequently and is often juxtaposed with terms that have higher public awareness.

- On the DLF website it is used in the way we've defined it here, as an umbrella term, but also as a supplementary term, e.g. 'assistive technology and disability equipment'.
- Assist UK uses the term 'assistive technology' infrequently on public-facing pages.
- Ricability notes a dilemma over this term. Ricability's job is to communicate information clearly and in everyday language. Using unfamiliar terms is alienating and disempowering. However, unless new terms are widely used they will never become part of the language. In relation to the term Assistive Technology, Ricability's style guide says:  
"...this is the generally accepted umbrella term for aids and equipment designed for disabled people. It is not widely understood outside professional circles. As a general rule we avoid terms that most people don't understand. Most of our *consumer* reports focus on particular equipment (stairlifts, walking frames etc) so there may be no need to use the term at all. If you do need to refer to AT equipment in a generic way you must explain the term the first time it appears in your text."

<sup>4</sup> Google Analytics figures for 2009 show that 'Assistive Technology' does not feature in the top 500 keywords used to find either main DLF website or 'Living made easy'

<sup>5</sup> Improving the Provision of Information about Assistive Technology, Wright, F., McCreadie, C., Tinker, A, June 2005, King's College London

However, a relatively low profile for the term Assistive Technology in public facing websites means that DLF, Ricability and Assist UK may not feature highly on Google search returns for the term 'assistive technology'. In order to manage this for their website DLF sponsors a link on Google for 'assistive technology'.

The conclusion of this for AT Alliance members was to feature the term 'assistive technology' on their websites more prominently wherever it could be used in an appropriate way and where it was unlikely to put off site users. This would increase the likelihood of search engines featuring AT Alliance members' websites in 'assistive technology' search returns.

### **1.3 Structure of the project and methodology**

#### **1.3.1 Phases of the Project**

The project is in three phases, over three years, April 2008 to March 2011:

- In Phase 1 2008/9 the Project Team completed early research, developed an AT Alliance website at [www.at-alliance.org.uk](http://www.at-alliance.org.uk), formulated a collaborative strategy, and carried out a survey of activities of the Alliance member organisations to consider future areas of potential partnership work.
- In Phase 2 2009/10 the Team worked on this project report covering activity and findings in year one; mapping the information environment, the challenges and opportunities. Stakeholders are being consulted on an ongoing basis which will inform the outcomes. Based on initial findings, the Working Group has developed a pilot project, a website guide ([www.allaboutequipment.org.uk](http://www.allaboutequipment.org.uk)) for improving access to equipment information which will be taken forward during 2010/11.
- Phase 3 will focus on evaluation, liaison with external partners, the final report, and dissemination of the findings, including launching the new website.

#### **1.3.2 Monitoring and Evaluation**

During the first year of the project, initial market research was carried out, looking in depth at the current ways in which people find out about specialist daily living equipment.

Further research in year two compared a number of AT equipment directories and analysed returns from questionnaires completed by stakeholders at a number of events around the country.

Following the development of the pilot website [www.allaboutequipment.org.uk](http://www.allaboutequipment.org.uk) in 2010, an online survey was created to gather feedback from key stakeholders to evaluate its effectiveness with a view to incorporating user feedback in the final version.

Results of the survey will be included in the final report at the end of the project.

#### **1.3.3 The project team**

The Project Board, made up of the chief executives of the AT Alliance organisations and chaired by DLF, meets quarterly, acting as the Executive Board overseeing the project.

The Working Group meets bi-monthly, with both CE's and development workers from the four AT Alliance organisations represented at different meetings. This group reports regularly to the Project Board. There are also sub-groups working on specific aspects of the project from time to time.

The project is led by a Project Manager, who reports to DLF's Chief Executive and chairs the project Working Group. The Project Manager works closely with DLF's Development Director and Finance Manager, who maintains and manages financial records for the project.

A Research Consultant has been engaged to conduct the market analysis, produce the market review report and carry out monitoring and evaluation over the period of the project.

## **1.4 Scope of the AT Alliance project**

### **1.4.1 Technology ‘clusters’ and categorisation approaches**

Assistive technology can be divided into a range of clusters as noted above. However, the use of illustrative lists or categories as part of a definition for ‘assistive technology’ can quickly become restrictive or irrelevant following the introduction of new technology. With this caveat, the project team felt it was important to have a broad brush overview of technology ‘clusters’ potentially falling under the umbrella term of ‘assistive technology’.

To do this the project team considered the use of a range of categorisation approaches: DLF’s thesaurus for DLF Data and ISO 9999:2007, those used in databases such as AbleData in the US and additionally checked against the ad hoc service clusters identified by FAST that correspond to existing and developing provision of technology-enabled services within health, housing, social care, education and employment sectors.

From a user perspective, many different individuals seek information; as disabled and older users of technology, as family members and informal carers, and as paid carers or practitioners. Much of the information is relevant to all, whatever the personal perspective of the information user.

Three important groups of information users that we considered as requiring a distinct set of information relating to specialist equipment were overweight people, disabled children and newly disabled parents. While disabled people may seek information due to impairments resulting from a specific health condition (e.g. MS, stroke, spinal cord injury, etc) it is not possible or viable to provide distinctly separate information using these categorisations as the resulting impairment is the defining characteristic irrespective of the causative health condition. There is also the potential to categorise technology and services purely according to task (i.e. to support memory loss, walking, etc) or by environment (for use in a learning environment, employment or play).

There was no consensus on any clustering that responded to a neat taxonomy and that also related to the ways in which people sought information or that was widely recognised as a sensible grouping. Therefore an ad hoc, high level categorisation of technology clusters and technology information requirements was developed in order to facilitate a detailed review by the project team of current information provision.

Rather than establishing the scope of the categorisation approach and the project itself by existing information provision by Alliance members, it was decided to set the scope of the project to include the wider range of technologies it would be expected that a disabled or older person may need information on. Reflecting FAST’s knowledge of technology and service development, Alliance members agreed that the scope of the project would include products and services likely to be more widely available on the market within five years, including telehealth, telemedicine, robotics, mobile phone applications (apps) and mobile navigation support.

### **1.4.2 Working with external partners**

An ambition for the AT Information Network project was to address the widely criticised fragmentation in information provision about assistive technology. This is recognised as resulting in frustration and is an ongoing problem for disabled and older consumers. The Office for Disability Issues (ODI) has looked at how disabled people’s access to information on public services can be improved.

“Strategies for improving and widening the range of information delivery channels should focus on offering individuals a cross-service route to information they need”<sup>6</sup>. Guidance has been produced for local authorities on how to make their information more accessible.

The Alliance members established early in the project that information about current assistive technologies should be produced by a wide number of organisations and for many local communities to suit their local context in a range of formats. The challenge for the project was to develop an initiative that would bring coherence to that information and improve quality without imposing rigidity or restricting or circumscribing who produced the information. The approach that would be adopted was one of partnership working within the Alliance membership and with external partners. The aim would be to produce a ‘framework’ or mapping exercise that would support and give shape and substance to the information already being provided and provide a trusted guide to access it. The development of such a framework would provide an opportunity to identify and support good quality information services whilst providing a coherent and straightforward information-seeking process for the public.

We also drew a distinction between processes which should not be duplicated, such as research and the collection of information, and those for which a proliferation of sources would be welcome, such as presentations and dissemination. An ideal would be definitive sources of information for particular areas which could be drawn on by those who could disseminate it in ways that suited their own style and audiences.

Additional issues considered by the Alliance members were:

- Much AT information provision reflects the fragmentation of service provision and effectively creates silos that have little meaning to the consumer. If a person has mobility problems they will experience these while travelling out and about, while at home, at work and at leisure. Technologies, particularly electronic assistive technologies, are becoming increasingly integrated and this needs to be reflected in the coverage of information about assistive technology.
- Feedback to Ricability at exhibitions and from telephone callers and emails sent via their website confirms their contention that reports aimed at and written for consumers are equally appreciated by healthcare professionals. Although improving the provision of information to disabled and older people is the main aim of the project, the Alliance agreed that all outcomes would be designed for and disseminated to practitioners as well as to the main audience of consumers.
- There was recognition by the project team that many people searching for information did not have an overview of the range of technology that was available; nor have the public been supported to understand the diverse quality of information provision so that they could recognise when they had found the optimal information service to meet their needs.
- Apart from information provision that fell within the Department of Health’s Information Standard ([www.theinformationstandard.org](http://www.theinformationstandard.org)), it was recognised that many individuals had no benchmark or criteria by which to judge whether AT information was independent of manufacturer bias, credible and comprehensive.

## 1.5 Conclusions on the scope of the project

At this stage in the review it was possible to draw some early conclusions:

1. In developing information provision there was a requirement to develop a cross-service route to information that a range of disabled and older people, their families and carers could use.

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<sup>6</sup> Five Principles for producing better information for disabled people  
[http://www.odi.gov.uk/docs/wor/imp/ODI\\_FivePrinciples\\_2007\\_main.pdf](http://www.odi.gov.uk/docs/wor/imp/ODI_FivePrinciples_2007_main.pdf)

In order to do this, there was recognition that 'horizontal links' between the information provided by AT Alliance members and other national level AT information providers should be reviewed for potential to enable an individual to navigate to information relevant to their life.

2. There is no clear taxonomy or categorisation approach that can be used to identify assistive technology content coverage by Alliance members and external partners. An ad hoc approach may need to be developed to enable an analysis of provision, gaps and deficits. A complication to an analysis that relies on a categorisation approach is that technologies, particularly electronic assistive technologies, are becoming increasingly integrated.
3. It became apparent from early discussions that quality standards were required by which consumers could differentiate good quality assistive technology information from poor.

## 2 Current state of the information market

### 2.1 Audiences for information

Alliance members report that audiences for their information include the following groups: the public; health and social care professionals; academics; statutory/ government organisations; multi-disciplinary teams in health and social care, voluntary organisations; and members of the AT industry<sup>7</sup>.

Based on DLF's regular monitoring of its Equipment Demonstration Centre and Helpline callers since 2002, the major groups of their AT information users are:

- Disabled and/or older people (c.50%\*) – seeking information for themselves
  - Carers (c.20%) – including family and representatives
  - Health Professionals (c.20%) – occupational therapists, physiotherapists, community nurses
  - Ancillary professionals (<1%) – manufacturers, designers, architects, others
- (\* % of visitors/ callers at DLF's offices, Harrow Road)

### 2.2 Numbers within audience groups and demand

**Numbers:** There is very little recent information relating to the numbers of disabled and older people who require or may wish to acquire assistive technology. At a headline level, the Office for Disability Issues<sup>6</sup> have updated DWP estimates which show there are over 10 million disabled people in Britain, of whom 5 million are over state pension age and 800,000 are children. Further figures for the numbers of disabled people and carers have been collated by FAST. The last large-scale survey of numbers of people with different impairments was the Family Resources Survey (FRS) Disability prevalence estimates in 2007/8. There is little indication of the need for or take up of different assistive technologies within these population groupings (some figures are provided for service users such as for orthotics and prosthetics, mobility equipment and community equipment, but these do not indicate overall demand).

For more information it is necessary to go back to the second large scale national survey of disability (published in a series of reports *OPCS Surveys of disability in Great Britain*, HMSO 1088-1989) which asked respondents if they used equipment in any of the following categories, and if there were other aids that might help that they did not have<sup>8</sup>:

- wheelchairs
- walking aids
- surgical aids and appliances
- vision aids
- aids to hearing
- incontinence aids
- small aids and gadgets
- special furniture and other aids to personal care

Caution must be used in interpreting this data since the range of equipment, its availability, means of supply and terminology have all changed in the intervening twenty one years since the survey was published.

The survey found that at that time 69% of disabled adults used some sort of 'disability equipment' and that this increased with an increasing severity of disability.

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<sup>7</sup> AT Alliance project, 2009 Research questionnaire

<sup>8</sup> *Disabled adults: services, transport and employment*. OPCS surveys of disability in Great Britain, Report 4, HMSO 1989, p45

**Proportion of disabled adults who used different types of disability equipment by severity category: adults living in private households**

Types of disability equipment	Severity category					All disabled adults
	1-2	3-4	5-6	7-8	9-10	
Wheelchairs	0	2	7	17	44	7
Walking aids	19	30	43	56	57	34
Surgical aids and appliances	14	17	20	25	20	18
Vision aids (excluding glasses)	8	11	14	16	22	12
Aids to hearing	16	15	14	16	17	15
Incontinence aids	2	2	6	11	34	6
Special furniture and other aids to personal care	27	32	45	58	70	39
Small aids and gadgets	6	11	18	28	30	14
Any equipment used	58	64	76	84	91	69

Use of equipment also increased with age. 45% of disabled adults aged between 16 and 49 used some kind of disability equipment, compared to 63% among those aged 50-64, 72% among those aged 65-74 and 86% among those aged 75 or more<sup>9</sup>.

In addition to equipment, the survey found that 24% of those interviewed had had some sort of adaptation made to their home. 35% of those with locomotor disabilities and 42% of those with personal care disabilities thought they might be helped by some sort of home adaptation that they did not have.

The survey that followed the OPCS surveys<sup>10</sup> and its successors did not collect information on equipment.

Similarly there is little information on the numbers of practitioners who need information about assistive technology. Some publicly available information on this can be obtained from FAST, collated in 2007 to inform workforce development proposals.<sup>11</sup>

It also is worth reiterating the fact that disability is not static. Most people will be affected by disability at some time in their lives, either directly through accident, illness or injury, or because of a close relative. Information in this area is therefore not a minority interest but one that concerns and is vital to the population as a whole.

**Demand:** There is currently little analysis available of the proportion of these audiences currently requiring information on assistive technology. There is also little marketing information on the demand that is unmet or the numbers of the public and practitioners who are unable to access current routes to this kind of equipment and who are unaware or unable to access equipment information.

### 2.3 Awareness levels

As a result of the lack of consistent and coherent information provision it was felt by Alliance members that there was a low level of awareness of the existence and potential of assistive technology and of routes to access information and equipment.

<sup>9</sup> Ibid, p46

<sup>10</sup> Grundy et al, *Disability in Great Britain*, Results from the 1996/97 disability follow-up to the family resources survey. Research Report 94, Department of Social Security, 1999

<sup>11</sup> FAST AT Workforce Feasibility Study, 2007 Appendix 5 Workforce data sheets

This was confirmed by some existing research:

- Tinker et al<sup>5</sup> described considerable difficulties encountered by older people in accessing information about AT.
- Which?, the consumer information organisation, carried out research in October 2009<sup>12</sup> that found a barrier for the public in choosing technology as a means to remain independent was that there was a lack of both information and clear access routes.
- Another important barrier to use was: 'Not knowing what I need/what's available'.
- Non- users were more likely to say they needed information than current users and when asked what would make them more likely to buy products, non-users are significantly more likely to say 'More information on what's available' than current users.
- 55% of people don't know which companies make these products and 45% don't know which shops sell them.
- A recent online DLF survey of parents with disabled children found that 73% of parents responding to the survey had not found it easy to find out about AT products.
- A similar online survey of users of DLF's prototype for 'Living made easy' ('Bathing made easy') found that 51% of people responding to the survey had not found it easy to find out about AT products.

## **2.4 Information availability on existing assistive technology**

In reviewing the scope of the project it had become clear that there was not a complete or equal coverage of the different assistive technology cluster areas by Alliance members. The project team undertook a review of where AT Alliance members provided information, set against the range of technology clusters falling within 'assistive technology' and identified the significant technology cluster gaps in that provision.

The analysis prioritised online comparative (database) information. The reason for this is that online information is arguably potentially the most accessible information format. It is also a format that can most easily support incidental information-seeking behaviour by linking between information sources. In this way it is a useful format to address the public's need to understand 'what is available on the market' and give an overview of products and services.

This analysis is available in Appendix 1. The analysis revealed that there were significant gaps in information provided by AT Alliance members about assistive technology online. The gap areas include the following broad technology cluster areas:

- Telehealth (not currently a mainstream service, but rapidly developing)
- Information Communication Technology (ICT) software (including switch control, interface options, access and formatting software, etc)
- Augmented and Alternative Communication (AAC) devices (related to ICT as there is an increasing cross over)
- Personal health care, rehab and medical equipment
- Prosthetics and orthotics (these have been provided almost exclusively through statutory services but this has changed over the past few years)
- Robotics and virtual reality (both are predominantly at a research stage although this will change within a 5 year time horizon)

There were also areas of information provision that were partial but which were assessed as likely to need expansion or partnership working either in terms of the breadth of technology covered or to bring hard copy information into an online format. These included the following broad technology cluster areas:

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<sup>12</sup> Which? Briefing: tools for independent living forum, October 2009: <http://www.which.co.uk/about-which/what-we-do/which-policy/health/long-term-care/index.jsp> accessed November 2009

- Posture support systems
- AT for sensory impairment
- Adaptations to housing and the built environment
- AT for cognitive support (excluding telecare products)
- Equipment for alternative leisure activities
- AT for driving, accessing public transport and for navigating the external environment (significant hard copy information on driving and related issues, funded by the Department for Transport, is available from the Forum of Mobility Centres and from Ricability, but little as yet online)
- Environmental controls and hardware and software for integrating electronic AT

## **2.5 Current routes for the public to get information on assistive technology**

### **2.5.1 National level assistive technology information**

Alliance members provide information online through access to databases on available products, guidance about choosing assistive technology through evaluation and user reviews, Ricability interactive databases, signposting to other information sources in the sector and through reports and publishing research findings. Much of this information is downloadable as hard copy leaflets, booklets and reports and some of it can be accessed through telephone helplines (DLF), through visiting the Alliance member centres (Assist UK network of Disabled Living Centres and DLF) and using tools such as AskSARA and DLF Data (DLF) located in external partners' websites. In this way Alliance members have a national presence and seek to make information available to organisations and communities at a local level.

Leaflets and small booklets about equipment are provided by Alliance members and are downloadable from their websites:

- DLF's Factsheets were downloaded 20,754 times in 2009 by people who directly clicked on links within the Factsheet section of DLF's website. However, this does not include the many other people who came across the Factsheets through search engines or links from other websites.
- All Ricability consumer reports are available online, many are also available as print copies and nearly 50,000 were disseminated to partner organisations (2009 – 2010)

For Alliance members it is not feasible to produce information in hard copy at a scale to achieve full market penetration due to lack of resources and a lack of distribution partners, i.e. sent out with relevant pension or benefits information.

Apart from that provided by Alliance members, information provided by the statutory sector at a national level has been negligible, though this is improving through the provision of information on NHS Choices and through some local authority websites, primarily in relation to telecare though also covering community equipment services. There is also some information on the developing retail model for the statutory provision of equipment which is being introduced in some areas. Information provided about assistive technology within the education sector, primarily to access ICT, was relatively well supported in the past, at a national level by the Government's agency Becta and by an online resource for students in higher education, TechDis.

The Department of Transport fund the Forum of Mobility Centres. They have funded the production of three editions of each of Ricability's thirteen reports on driving and car adaptations and two editions of their guide to using a wheelchair on public transport. There has yet to be an online format for this information. Little freely available information is available from Communities and Local Government on housing adaptations beyond Lifetime Homes guidance, though information is available from third sector organisations such as Foundations, the umbrella organisation for local Home Improvement Agencies.

Information is available from the Centre for Accessible Environments who provide information by telephone, textphone, fax, letter or email on all aspects of designing for accessibility, including the implications of the Disability Discrimination Act 1995 (DDA). This service is free of charge, though design guidance books and audit tools are available only through sale.

The default position for many information services to assist people looking for assistive technology, Directgov being an example, has until recently been to signpost to local Occupational Therapy services usually via the Local Authority or PCT<sup>13</sup> as well as to DLF, Assist UK and Ricability. Increasingly they are providing information more closely tailored to specific groups of people such as disabled parents and those people recently disabled.

**NHS Choices** provides similar advice:

“Equipment for independent living is usually provided by your local health authority, through your social worker or occupational therapist. Your GP can refer you to either of these specialists.”<sup>14</sup> [NHS Choices: “How do I get assisted living equipment’ section.]

“For information on what’s available and where to get it from, speak to your GP or practice nurse, local pharmacist or social care staff.

#### **How to get more help**

- For more advice on equipment to help you manage around the house, visit the Directgov website.
- Phone social services at your local council and ask for a home assessment.
- The Disabled Living Foundation (DLF) can also give free advice.” [NHS Choices: Live Well/ Get the right equipment]

“You can gain access to this equipment by arranging a community care assessment for the person you’re looking after (or an assessment under the Children Act if the person you’re looking after is a child).” [NHS Choices: Carers direct/ Care at home] (This section also provides several external links including to DLF, Ricability and to Assist UK and their membership centres.)

The default position for these government-funded sites has to be to refer to local community social care and occupational therapy services and many of them are good and are provided free or at low cost. However, services around the country vary widely in quality and they may also be considered to be poorly accessible due to long waiting lists, or inappropriate due to lack of clarity about eligibility for assessment and advice.

There is also diversity in the range of equipment that is offered across the country by different Community Equipment Services and available to those eligible for statutory provision. This may well be the product of the laudable intention to make services locally responsive, and devolve policies to those who work close to the communities they serve. However, there are problems relating to inequality of service with no minimum standards on equipment provision across the country. For example, none of these services offer a full range of communication aids to aid speech and many will not provide equipment for leisure and social activities, for example, to enable people to access their garden or leisure pursuits, getting into or out of a car or in relation to public transport. There is also no ‘standard inventory’ against which one can identify if a local service stocks or provides a particular product or range of devices.

As an alternative to statutory provision, there are options for self purchase and it is possible to get advice from a limited number of private occupational therapists.

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<sup>13</sup> Direct.gov.uk identifies “Trying, choosing and buying equipment” which signposts people to DLF and mentions Occupational Therapists <http://www.direct.gov.uk> accessed June 2009

<sup>14</sup> NHS Choices: <http://www.nhs.uk/carersdirect/> accessed March 2010

The College of Occupational Therapists has a directory of occupational therapists in independent practice at [www.cotss-ip.org.uk](http://www.cotss-ip.org.uk) which can be searched to identify practitioners who say they have experience in equipment.

Many national level services will signpost to DLF, to Ricability and to Disabled Living Centres under the Assist UK umbrella. Condition- and impairment-focused voluntary sector organisations often omit to provide information on AT and will usually refer to other sources, such as DLF or to occupational therapy services. The exceptions to this include the RNIB and RNID who provide an online shop as well as information on relevant technologies. AbilityNet, a charity supporting disabled and older people to access ICT provides some free assessment, advice and guidance services to disabled and older people, at home, work or at a learning establishment, as well as a range of paid for services. The level of demand relating to assistive technology from users of voluntary sector information services is unknown. Radar, a national pan-disability charity, produces a hard copy national guide "If only I'd known that a year ago..." for newly disabled people, their families and friends which signposts local services and information resources including those in a position to give advice on assistive technologies.

From discussions with third sector organisations there appears to be an increasing interest in providing information to their members about assistive technologies, particularly in relation to more innovative technology services such as telecare. National level third sector organisations such as Age Concern provide useful introductory information on telecare and also have a trading arm, AidCall, who provide a telecare service. Given that Help the Aged sell stairlifts via their online shop it may be that these organisations have more ambitious plans when fully merged into Age UK.

A consultation exercise carried out at Naidex 2009 (the questionnaire used is shown at Appendix 4) indicated that people would expect their GP or local pharmacy to know about equipment or at least to be able to point them in the right direction. Unfortunately this is not the case at present. Practitioners such as Doctors, Occupational Therapists, Physiotherapists, Speech and Language Therapists may not themselves feel confident or competent to give advice on a range of technology options. Most practitioners are not supported by their education to be confident or competent to assess for many types of AT, though some practitioners achieve this through work experience. Half of all practitioners across the workforce will have no relevant AT education<sup>15</sup>. GPs will have little or no education in assistive technologies.

Much information provided at national level by Alliance members as well as locally is derived from the information about products provided by manufacturers. Nearly all manufacturers describe their products in brochures and leaflets. These are probably more widely distributed than any other information about AT equipment. They are used by consumers and also by prescribers of equipment who often assemble and maintain loose leaf folders of this information from which they prescribe. Manufacturers' and retailers' information can also be accessed directly online by practitioners and potential consumers.

In terms of the technical information provided by manufacturers, either online or in material accompanying the product at point of sale, there is no agreement on a 'standard set' of information. There are no standards or codes of practice that provide guidance on what information should be provided as a minimum, or about how individual measurements should be made to provide some consistency across manufacturers. As a result this source of information does not support comparisons between products. The provision of information is often not identified by people as a separate resource to the service they are receiving. The information provided by manufacturers also does not necessarily provide the information of most significance to users. Ricability notes that, if information includes user comments and tips, this can help to make the information more interesting and practical in real-life situations.

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<sup>15</sup> Assistive Technology: an education, a career, a partnership, AT Forum, November 2005, <http://www.fastuk.org/atforumactivities/workforcedevelopment.php>

## 2.5.2 Local level information

The internet has considerable merits: in flexibility, interactivity, ease of updating, use of graphics and lack of the practical constraints of paper based information. However, it is unlikely to supplant paper-based information; the two media are complementary. There is thought to be a significant level of information cascaded down from national to local networks and individuals, through the download of online information, but it is not possible to quantify this accurately. There is the potential to provide good quality information produced online at national level and then worked on to be made relevant at local level. However, resource issues mean that this often has to be undertaken at the expense of local services and few policy or practice drivers exist to make this a priority or to make funding available.

Assist UK acts as an umbrella organisation for membership of Disabled Living Centres (DLCs) (also known as Independent Living Centres and Assistive Technology Centres), each of which demonstrates and provides information about a varying range of equipment across the country. The Disabled Living Foundation, in addition to providing a national information resource, acts as the local Disabled Living Centre for Westminster Council.

There is variation in the information provided by DLCs, with some able to provide information on equipment which has been highlighted as not covered by the DLF's "Living made easy" website or on DLF Data. A limited number of DLCs, for example, have on show a range of software for accessing ICT and many will have a limited range of low vision aids and equipment for people with a hearing impairment.

In addition, Assist UK requires its centres to provide information on equipment to manage continence though they report a variation between centres in how prominently these products are displayed. DLCs will have information and signpost to specialist centres that supply orthotics and prosthetics and other specialist services. A number of DLCs will have sensory surround rooms for people with a learning disability and some DLCs will have information on the Blue Badge navigation system while some are also driving assessment centres (about 5 of them).

This review of local information and demonstration centres has highlighted the need for an inventory of local DLCs' demonstration facilities to enable members of the public to identify where best to go to try out different ranges of equipment. This review also highlighted the fact that many local authority areas do not have a DLC as there are currently only around 50 across England.

Many local authority social services departments have purchased online information resources to support their information provision. StartHere is an example of an information portal, purchased under licence for use in local authority areas, which provides information on a wide range of health, care-related and other social issues, though it does not cover assistive technology. For assistive technology many local authority occupational therapy services and Community Equipment Services use DLF Data and also either AskSARA or ADL SmartCare. These latter information portals are available to the public by visiting the relevant websites, some of which provide local information sponsored by local authorities. Support to access the internet for this purpose is provided at DLCs and some other local organisations.

There is also a range of other information providers at a local level who provide some information on assistive technology. Dial UK is a national organisation overseeing a network of approximately 120 local disability information and advice helplines run by and for disabled people. Local disability support groups will provide a range of information, some of it very good and locally targeted but often this is fragmented and out-of-date.

Citizen's advice centres, carer information services and local authorities provide helplines, and information about local equipment display and demonstration centres (if there are any in the area) and also signpost to local retailers.

Manufacturers and retailers, including large high street stores such as Argos and B&Q, provide an increasing but limited range of assistive technology in store and online. The range of equipment available in these large high street stores is restricted and staff are unlikely to be able to provide much relevant information. There are increasing numbers of specialist assistive technology stores whose staff can be well informed and who may be able to provide credible information that meets the needs of their customers, though much of the information provided will relate to the range of products offered for sale.

### **2.5.3 Online forums and user reviews**

A number of online forums exist where older and disabled people and their families and carers can discuss issues affecting them, including the provision of assistive technology. These forums do not all attract high volume and contributions are intermittent because peoples' experiences are so varied and information is relatively hard to find. As a consequence the quality of advice is varied.

DLF has had an active forum in the past and launched a new forum in 2009 that is included in its main [www.dlf.org.uk](http://www.dlf.org.uk) website as well as 'Living made easy'. The forum allows users to ask questions of each other and DLF's team of occupational therapists.

Many other voluntary sector organisations have active forums (for example, RNIB, RNID, Scope and Carers UK). Most of these forums focus on different issues (e.g. work, living, health) but these do not necessarily include areas specifically about the use of assistive technology or equipment. One exception is RNID, which has a forum dedicated to Products and Equipment that links to their online shop. The education sector has a specialist forum for Special Educational Needs (SEN) practitioners, SENIT, as do specialist electronic assistive technology practitioners, Assistech. On the whole these are not publicised to, or accessible by, the general public.

Probably one of the most popular forums used by disabled people is BBC Ouch! although this does not have a specific forum relating to assistive technology. The Youreable site used to have a forum specifically on Mobility Aids and Equipment but this is currently unavailable. Enabled by Design is a new online community that aims to allow users to review products and provide feedback, with a view to improving the design of assistive technology to meet the aspirations of older and disabled people.

Many people are familiar with the limitations and scope of online user reviews, understanding that the information and guidance is provided by the individual and relates only to their own case. Other users can then decide for themselves if this is useful to their situation. However, obtaining a critical mass of users willing to write reviews in such a specialist area can prove difficult – even websites with broad appeal and significant levels of traffic, like Amazon, only have a small percentage of users who add reviews. The risks and processes for managing user-provided reviews have been clarified in other fields, e.g. Amazon, etc. and the potential for links between DLF's 'Living made easy' site and Ricability's user review section will be reviewed in year three.

### **2.5.4 Telephone helplines**

DLF offers and advertises a telephone helpline and follow up service to help the public and practitioners to identify different equipment. This is a relatively resource-intensive service and many other voluntary sector organisations have cut this aspect of their service due to costs. DLF received over 25,000 enquiries from April 2009-March 2010 with three Helpline staff. Take-up is again limited by awareness levels among the public and calls are primarily from the South East (possibly because other areas call their local DLCs). Currently resources limit the range of languages spoken on the helpline.

Some Disabled Living Centres and Ricability also support the public who contact them by phone to identify assistive technology solutions. Enquirers are given all the help Ricability can provide and the majority are put in touch with DLF. This is not a formal service and so is not publicised.

FAST similarly signposts members of the public to relevant information sources but does not support the public or practitioners to identify specific pieces of equipment. The Dial UK network who run helplines around the country signpost callers to equipment services when appropriate but have no data on the number or proportion of these callers.

### **2.5.5 Exhibitions**

There are a number of exhibitions and events held across the country where people can see products displayed and meet with suppliers. DLF lists these on its website and FAST includes these exhibitions on its online listing of assistive technology events.

The largest exhibition in the calendar is NAIDEX, held in the Birmingham NEC every April. Organised by Emap Public Sector, this is attended by nearly 12,000<sup>16</sup> people (38% Healthcare Professionals, 33% public, 29% trade). The exhibition includes a broad range of suppliers. DLF acts as the Information Point at the show every year using DLF Data to answer queries from attendees and direct them to both suppliers exhibiting at the show and those who are not. Ricability also usually exhibits here. Emap additionally organises Independent Living Scotland, which is held every two years, and NAIDEX South, which was launched in 2010.

The Mobility Roadshow is held every summer and focuses on motoring and mobility products such as wheelchairs, scooters and buggies. This is a popular show and people are able to test drive vehicles. Ricability normally exhibits here.

Other longstanding events aimed at the public include the Disability North exhibition and Kidz up North/ Kidz in the Middle/ Kidz down South, all organised by Disability North. DLF now exhibits at the Kidz exhibitions to raise awareness of 'Living made easy for children', its website on children's equipment funded by the Department for Education.

#### **Lifestyle exhibitions**

In the last couple of years other companies previously focused on mainstream products have begun to provide assistive technology products, presumably to take advantage of the growing ageing population and the perceived spending power of disabled people. New entrants include Beyond Boundaries, No Limits and Enable. However, as most events rely on funding from exhibitors from the equipment industry to survive, in light of the current economic situation which is squeezing companies' marketing budgets it is too early to tell how many of these shows will remain viable. Already some of these shows seem to have fallen by the wayside with no dates announced for 2010.

#### **Exhibitions for professionals**

In addition to these shows, which are aimed at professionals and the public, there are a number of conferences aimed solely at professionals where new products can be seen. These include the College of Occupational Therapists' annual conference, RAATE, National Back Exchange and DLF's Moving & Handling People conference.

### **2.5.6 Media, advertising and marketing**

Assistive technology has a relatively low profile in the mainstream media and in advertising campaigns. A poster campaign at bus stops has been undertaken by organisations such as London Telecare but there is no information available on whether this has driven up demand and, if so, in what market segments.

During its 40<sup>th</sup> Anniversary in 2009-2010 DLF worked with a PR agency to raise its profile and the profile of assistive technology. However, it is unlikely to have the funds to sustain this level of awareness-raising in the future.

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<sup>16</sup> NAIDEX 2010 attendance figures: 11,618 (ABC audited)

## 2.5.7 Education, training and confidence building sessions

Another route to providing information is through education provision, through training courses for practitioners and confidence building courses for disabled and older people. DLF and Assist UK provide training for practitioners in a range of assistive technology cluster areas. FAST provide a full listing of the training and education provided across assistive technology at a range of educational levels.

The FAST mapping exercise identified that there is no national qualification framework for assistive technology and consequently much training and education is unsustainable due to lack of funding and students. There is also a lack of coherence on core skills and knowledge due to the ad hoc development of training in this area, mirroring the fragmented service provision that characterises this area. There has been some Trusted Assessor training available to disabled and older people, health care professionals, Housing Associations and retailers provided by Assist UK, though this course is currently under review. FAST is developing an introductory set of learning and confidence-building materials to support disabled and older people to build confidence to choose and use technology for self care. Achieving information penetration within the general population through these routes is likely to be variable but overall this is likely to be small scale.

A recent online DLF survey of website users and a sub-set of parents with disabled children identified that they had used the following sources of information:

Information sources used:	All users %	Parents %	
Magazine/newspaper adverts	16	10	
Internet	32	33	
Social Services	13	7	
Voluntary Service Organisations	11	10	
School	<1	12	
Friend/family	11	14	
Doctor/Health Centre	11	7	
Other	5	7 <sup>(a)</sup>	<sup>(a)</sup> exhibitions (e.g. NAIDEX) significantly cited.

## 2.6 Effectiveness of these formats to provide access for different audiences

Having identified that information about assistive technology at national and local level was provided through a range of organisations and in a diversity of formats, the relative effectiveness of various formats were reviewed:

- online
- face-to-face
- by phone
- hard copy
- TV and radio adverts and information presented through the media

There is little analysis that we were aware of that indicated which, if any, formats were more accessible to and effective with different audience groups, nor which were most effective in stimulating private purchase or consumer-influenced purchasing through statutory services. Preferred formats appear to differ depending on age, education, affluence, first language, internet use, etc. The consensus is that providing information in a range of formats is most effective, particularly to penetrate local information networks.

*Information needs to be available in a range of formats, a range of accessible places, and in a range of different styles, of presentation and content.*<sup>17</sup>

<sup>17</sup> The revolution in equipment supply and what it means for information. Ricability, 2009

Provision of information in a range of formats can be expensive and local authorities struggle to find the resources to do this just as much as smaller organisations.

### 2.6.1 Online

There are concerns that information provided primarily online excludes older people. There is, however, a significant increase in the take up of the use of home computers and internet access by older people. Regular ONS surveys indicate that the proportion of the over 65 adult population who had used the internet in the last 3 months rose from 16% in 2003 to 26% in 2008, also the percentage of over 65s who had never used the internet fell from 82% to 70% between 2006 and 2008. In 2008 26% of over 65s who had recently used the internet had been seeking health related information.<sup>18</sup>

Problems with accessing online information are apparent in an extensive survey of internet use by disabled people by the Office for Disability Issues. This found that 42% of respondents used the internet currently or had used it recently. This was lower than the general population (67%). In all age bands it seems that disabled people were less likely to use the internet compared to the non-disabled population, but again younger people are more frequent internet users than older people: 80% of those aged 16-34 had used the internet compared with just 10% of those aged over75.<sup>19</sup>

A survey in 2005 indicated that up to at least 50% of adult carers may be using the internet. Half of those surveyed had previously used the internet and 61% went online once a week or more frequently<sup>20</sup>.

Alliance members monitor their website ratings using search engines, such as Google, and action taken on the information gathered can have a significant impact on how well they reach their intended audiences:

Assist UK is updating its website in 2010/11 and will have monitoring information available in Year 3.

DLF uses Google Analytics to monitor traffic to its main website, to 'Living made easy' and to AskSARA, its guided advice tool.<sup>21</sup> Figures for 2009-2010:

- DLF's main corporate website received c.238,000 visits (c.184,000 unique visits) and c.760,000 page views – 74% were new visitors
- 'Living made easy' received c.410,000 visits (c.350,000 unique visits) and c.1,600,000 page views – 83% were new visitors
- AskSARA received c.36,500 visits (c.29,000 unique visits) and c.382,000 page views – 78% were new visitors

Ricability uses Google Analytics to track use of its website. Statistics for 2009 – 2010 indicated:

- an annual traffic of 161,000 unique visitors
- 78% were new visitors and 22% were people who have visited before
- between them, visitors looked at 560,000 separate pages

Nearly half the site visitors (46%) were using a search engine to find a particular piece of information: a third came directly and just over a fifth (21%) were referred from another site.

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<sup>18</sup> Office for National Statistics Internet Access: Household and Individuals, 2003, 2007, 2008.

<sup>19</sup> Office for Disability Issues, 'Experiences and Expectations of Disabled People', 2008.

<sup>20</sup> Blackburn, Read and Hughes, Health and Social Care in the Community, 13(3) 2005 pp201-210.

<sup>21</sup> Figures for 2008-2009 show traffic of c.270,000 visits a year to DLF's main website, 380,000 visits to 'Living made easy' and c.19,000 to AskSARA.

Over the year some 750 third sector, statutory, commercial sites referred their own visitors to Ricability's website through permanent links.

FAST uses a custom analytics programme and is currently reviewing the data it receives.

The AT Alliance members make all efforts within the restrictions of their resources to ensure that their online information is available as widely as possible at the highest level of accessibility possible. Assist UK understand that their site adheres to minimum standards and aims to get improved accessibility when resources allow. FAST's site is designed to be fully accessible in line with current web standards but insufficient resources mean that it has not been fully tested by users. The Ricability website meets the WAI AAA standards for Accessibility. DLF aims to meet WAI AA standards and regularly user tests its websites.

### **2.6.2 Face-to-face**

There are anecdotal indications that people value getting information through face-to-face contact with trusted professionals such as GPs or Occupational Therapists (OTs), clinical and service practitioners, from peer networks and voluntary sector organisations, and from local retailers. There appears to be no information on which segments of the population particularly value face-to-face discussion, nor how face-to-face interaction impacts on choices about acquiring assistive technology, adoption and satisfaction rates, etc.

Education and training courses could be particularly useful to spread information to practitioners but few will have geographical access to the limited number of courses that exist and may also be excluded from attending educational courses as competence in assistive technology has not been recognised and supported at a national level, so funding and time released from work is unlikely to be available. Confidence building and awareness raising courses for disabled and older people and their families could address the lack of information available through other information routes and be particularly useful for raising awareness of the potential of assistive technology with older people.

### **2.6.3 By phone**

Information provided by phone may be more accessible to people who are blind or vision impaired and may be particularly valued by older people and those practitioners who do not have access to the internet. Although the amount of information given over the phone will be limited, almost everyone has a home or mobile telephone which makes this the most accessible medium for most people.

### **2.6.4 Hard copy**

Providing the facility to download hard copy from the internet may be a particularly useful format to reach seldom contacted population groups. Paper based information can be *proactively* delivered to people who would not come across it otherwise, and particularly to people who do not know they need information, never look for it or assume that it just does not exist. The advantages of paper based information include its convenience for those who like to digest information in chunks away from the constraint of being near a screen. It is passed around by informal networks. It is less tiring to read and can present tabular information, such as the comparative performance of competing brands, in a way that is intuitively easy to understand.

Hard copy information, suitably formatted, may also be particularly accessible to people with a learning disability, for those people who have no access to the internet and for those who are not actively seeking information but who may value information provided concurrently with other services (for example at a GP surgery, or at Post Offices, accompanying Driver & Vehicle Licensing Agency (DVLA) notices, etc.).

## **2.6.5 TV and radio adverts and information presented through the media**

The project team felt that mainstream advertising and media portrayal of assistive technology could be particularly influential in raising awareness of what exists and stimulating information-seeking from a broad range of people in the population. Outside of the increasing profile of disabled actors in soap operas and some reality shows featuring disabled people, there is a concern that portrayal of assistive technology tends to occur within silos. Magazine and television adverts for assistive technology products tend to target older people and their families in connection with programmes of interest to older people and could be seen to stigmatise these products as unattractive to younger disabled people or those living more active lifestyles.

A concern relating to retail marketing of assistive technology is the potential for unethical selling practices, as identified by Age UK and Consumer Direct. This appears to be particularly in relation to the sale of expensive equipment to older people. The trade organisation for assistive technology retail sector, the British Healthcare Trades Association (BHTA) have responded to this concern by developing, with the Office of Fair Trading (OFT), a Code of Practice to which their members must comply. Within the context of responsible selling, Alliance members felt that increased advertising and marketing of assistive technology would serve to raise awareness and stimulate information seeking by the public.

## **2.7 Conclusions on information provision and preferred formats**

From our review of current information provision and the awareness level and information penetration of different market segments the project team drew the following conclusions:

1. Audiences for information on assistive technology are varied as is their motivation for seeking information and also their information seeking behaviour. Numbers and demand from different audience groups are relatively unknown, as is the level of unmet need. Despite this, Alliance members felt strongly that the need for information is widespread and urgent, based on their experience and correspondence with audience groups, including some survey and website analysis.
2. To meet the project ambition to develop a one-stop shop, a strategy would need to be developed to enable the public to easily identify solutions from a broad range of technology clusters, some of which are not covered or covered to a limited degree by AT Alliance members. It was agreed to review the potential for 'horizontal links' with other national level information providers.
3. It became clear that the public needed a guide to support them to understand the information 'landscape': where to go to find sources of information and to be alerted to information resources. Such a guide could also be used to identify where no information existed in order to reduce an individual's frustration at not finding information which they believe exists but doesn't. The guide would need to encompass a range of purchase and access methods for assistive technology, from statutory provision, private purchase, rental, previously used and recycled.
4. The review of information resources demonstrated the need to strengthen links to national level information resources such as Directgov and NHS Choices. At a local level it became clear that strengthening links with local information networks such as Dial UK and citizens' advice centres would also help to reach significant numbers in the population.
5. It was agreed that it would be good practice to set out the quality standards by which consumers could differentiate good quality AT information from poor, drawing on existing good practice such as the Information Standard.
6. Achieving a cascade of information from national level to local level was highlighted as important and a range of methods were reviewed.

These included leaflets and booklets, downloadable information from the web and the use of new information formats, etc. No clear solution was apparent and there were restrictions for each option relating to disproportionate costs. It was agreed that this issue required further consideration during year three of the project.

7. Although GPs were felt to be key information partners for health information, the DLF survey noted that for assistive technology information, friends and family were identified as more likely to be a source of information. Alliance members were unsurprised by the public's assumption about the relatively low level of knowledge and information held by GPs but recognised that health centres and GPs are quoted as health information portals. Alliance members considered funding location-specific video displays in GP surgeries.
8. In addition to links with other national level online assistive technology information providers, the project team identified a need to support a broad range of third sector membership organisations to provide more information on their sites relating to assistive technology. This will be reviewed as a potential activity in the third year of the project and as part of the dissemination activity.
9. Ensuring that the information provided by Alliance members was available as widely as possible is a priority. It was agreed that one area of potential collaboration was to share information and resources in order to maximise the accessibility of information provided in hard copy and online. A priority for any information one-stop shop would be to ensure maximum access for people with a range of impairments and also to identify whether resources existed for translation of existing information for UK residents for whom English is not their first language.
10. Further review was required of the information provided by manufacturers and some analysis of whether a 'standard set' of data could be established. A further piece of work was proposed to look at how to exercise maximum leverage on manufacturers to provide a particular range and quality of data and information about products and services.
11. It was agreed that it would be useful to provide comprehensive information on the equipment that could be viewed and demonstrated in the DLCs around the country. Further review of this issue was noted as a priority.
12. The effectiveness of forums and user reviews to provide peer support and information on assistive technology was recognised, particularly in view of the lack of other evaluation data published nationally. Further work to identify a sustainable strategy to develop this kind of information sharing activity would be undertaken, including reviewing the potential for 'horizontal links'.
13. Attendance at a range of specialist and generalist exhibitions by Alliance members was noted as one way to contact many people who have already engaged in information seeking about assistive technology and are some way down the path. The potential for sharing costs by developing a collaborative 'communications' strategy was noted for action.
14. Whilst it was acknowledged that mainstream media, advertising and marketing approaches would serve to raise awareness among those people newly disabled or beginning to experience the effects of age, and their family members, the cost of such campaigns would be prohibitive to Alliance members. However, any opportunities arising to undertake such activities will be pursued.
15. In line with existing activity, there was agreement on the desirability of shaping the market positively by prioritising information about those retailers who are voluntarily complying with relevant Codes of Practice. Ways by which quality standards could be highlighted and supported was noted for further review.

16. Good information, and its effective delivery, has a price tag. All of the points listed above have implications for the allocation of resources. Alliance members are conscious that it is disproportionately difficult to fund information resources since they are not seen as a frontline service or being in need of separate funding. Yet the evidence shows that appropriate and timely information is the key to the take up of assistive technology and to independent living.

### 3 Predicted state of information market

#### 3.1 Market change

##### 3.1.1 Numbers and demand

That Britain will undergo a significant demographic shift towards becoming a predominantly older population is well known and we won't review the figures in detail here. In summary the percentage of the population aged under 16 has been declining since 1995 and, for the first time ever, has dropped below the percentage of the population of state pension age<sup>22</sup>. Current UK population growth forecasts<sup>23</sup> are shown below:

	<b>Growth over next 10 years 2018</b>	<b>Growth over next 20 years 2028</b>
Over 50s	3.5m (17%)	6.2m (30%)
Over 65s	2.3m (24%)	4.9m (49%)
Over 80s	640k (25%)	2.2m (79%)
Total population	4.5m (79%)	8.6m (14%)

It is widely accepted that impairments and dependence increase with advancing age and the number of older disabled people has been forecast as likely to increase by 40% between 2002 and 2020 if age-related disability rates remain constant<sup>24</sup>. Lifestyle changes will contribute to an increasingly unhealthy population which will give rise in turn to an increased incidence of impairment, e.g. in 2008 the Government Foresight Project predicted that nearly 60% of the UK adult population could be obese by 2050<sup>25</sup>.

ONS reports show that the UK population has been living longer over the past 23 years, but that the extra years have not necessarily been in good health or free from illness or disability. A study undertaken for the ODI has specifically reviewed future disability trends<sup>24</sup>. This study forecasts that the number of older disabled people would be likely to increase by around 40% between 2002 and 2020, if age specific disability rates remain constant.

In addition to an increased number of older disabled people, it is forecast that there will be an increasing number of disabled children. The General Household Survey estimated the number of disabled children under 16 in Britain in 2002 to be 770,000, out of a population of 11.8 million children. By 2020, the total number of children is projected to drop to 10.8 million, but it is widely anticipated that the proportion who are disabled will have increased. The drivers of the increase in disability among children and young people are not well understood but might include improved diagnosis, reduced stigma associated with reporting disability and better survival rates for pre-term and disabled infants.

The impact of living with impairment is not restricted to the disabled individual. There are currently around 5.2 million carers in England and Wales and more than half are over the age of 55. More than 1 in 5 of people aged 50 – 59 are providing some unpaid care. In 2004 the majority of informal carers aged 65 and over themselves reported limiting, long standing illness. Carers are estimated at 20% of the current purchasers of assistive technology.

In summary the Alliance members concluded that the market for assistive technology and related information, if one were to base this solely on the increasing numbers of disabled and older people in the population, is likely to grow between 30% - 50% over the next decade as a conservative estimate.

<sup>22</sup> The Age Agenda, Age Concern, February 2008

<sup>23</sup> Office for National Statistics, 2009

<sup>24</sup> <http://www.officefordisability.gov.uk/iod/background/background0101.php> (ODI, Images of Disability)

<sup>25</sup> <http://www.foresight.gov.uk/Obesity/Obesity.html>

### **3.1.2 Demand for assistive technology information**

According to recent market analysis<sup>26</sup> sales of disabled equipment in the UK have increased by 92.6% over the last 10 years and the total market size increased by 9.2% in 2009. The total UK assistive technology market has been estimated at £1.46 billion for 2008 compared with £1.34 billion in the previous year<sup>27</sup>. Of the 1.53 million clients receiving state funded community-based services, 519,000 clients received equipment and adaptations<sup>28</sup>.

Continuing market growth has been predicted and, although this forecast predated the onset of the current financial recession, it did anticipate lower increases in NHS spending from 2008 and a possible downturn in the economy. The view taken was that the market was unlikely to be greatly affected by any downturn in the economy, since people are likely to spend money on essential equipment whatever the state of their finances. Governments are reluctant to cut expenditure on healthcare even in times of hardship, due to the political sensitivity of such measures, although anticipated cuts in local authority budgets may mean that access criteria levels for social care services including the provision of equipment are raised in order for local authorities to manage demand on reducing budgets for equipment provision.

### **3.1.3 Changing attitudes to technology**

There is sector consensus that more technology confident and assertive, “baby boomers” who will be required to work longer into their older age, are not going to be prepared to put up with barriers to employment and delays in receiving equipment. Additionally there is consensus that attitudes towards health care purchases will become more consumer-oriented, with many people being less willing to accept basic-level state services. The rise of the use of special interest online forums and social networking groups focused on information sharing around impairment and health conditions indicates the potential development of a more information-savvy customer base for assistive technology.

### **3.1.4 Technology diffusion**

The development and more aggressive marketing of telecare is also anticipated to drive the assistive technology market, which has remained fairly stable in terms of design and innovation. The potential market growth in electronic environmental technologies that integrate with mainstream ‘infotainment’ technologies in the home is seen as significant. This cluster of technologies is also more likely to appeal to younger consumers who are resistant to purchasing other technologies that are seen as stigmatising. The Which? Research indicated that over half of all potential purchasers who responded to the survey ‘would hate to think they’d ever have to use these products’. There is also the potential that integration with mainstream, high volume technologies will bring down the cost of this equipment, although balancing this is the fast development of all technology which may act to keep prices high. There is also a concern that any influence Alliance members are beginning to have with assistive technology manufacturers may be irrelevant to mainstream manufacturers in a global market. There is also a challenge to assistive technology information provision as a relatively structured market place with clearly defined products becomes integrated with mainstream technologies. It is to be anticipated that Alliance members will be providing information on grey area technologies such as iPhone apps that are designed to enable independence for disabled and older people, in other words, mainstream devices and software that operate as assistive technologies.

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<sup>26</sup> Plimsoll Portfolio Analysis (Disabled Equipment) First Edition 2009, Dec 2008), pp2.1 a and b.

<sup>27</sup> Key Note Market Report 2006, ‘Equipment for the Disabled’ (ISBN 1-84168-8975)

<sup>28</sup> Community Care Statistics 2007-08: Referrals, Assessments and Packages of Care for Adults, England, National report and CASSRs, NHS Information Centre, May 2008

## 3.2 Policy drivers

The policy context for the provision of – and information about - assistive technology is shaped by the wider social and economic situation. Central challenges addressed by policy are the demographic pressures on resources, the economic downturn, and changing attitudes about individual versus state responsibility for managing health and social care needs. The key policy themes are set out below with a separate listing of some relevant policies in Appendix 2.

- **Resources:** The first policy area impacting on assistive technology services is that of proportionately reducing resources. The options for transforming the way in which resources could in future be allocated have been set out in the recent Green Paper, “Shaping the Future of Care Together”<sup>29</sup>. A new National Care Service was proposed by the previous Government and the recommended funding options (all excluding care home accommodation costs) were: “partnership” – the state meets a proportion of care costs (up to 100% for those on low incomes), “insurance” – people choose to indemnify themselves for a one-off payment against care costs in retirement not met by the state, and “comprehensive” – people over retirement age who can afford to do so have to make a one-off payment and are then fully covered. The focus of much of the subsequent proposals coming forward from Labour and Conservative has been on personal care and residential care, with little specific mention of the relative resourcing of assistive technology services. What is clear is that there will be a higher level of personal purchase of equipment and there will be some support to develop a more diverse market and to support the provision of information that will support the expansion and maturing of a consumer market in this area.
- The proposals around shared financing build on the perceived success of Personal Budgets within social care services. Personal Budgets are a key component of personalised care services and, whether notional or actual, are seen as giving the user the power of a consumer. In the longer term “everyone eligible for statutory support should have a personal budget - a clear, up-front allocation of resources”<sup>30</sup>. There are widely voiced assumptions that providing personal budgets will, in itself, develop the market for assistive technologies. Given the lack of awareness by the public, the low profile of consumer-facing retailers in this area, the poor championship of technology as an option by practitioners, brokers and advocates and the out-dated design of much current equipment, these are assumptions that cannot be assumed to be valid. In addition, in April 2009 the Department of Health proposed to pilot personal health budgets from summer 2009. As dependence on Personal Budgets increases and awareness grows around their implementation and potential for purchasing equipment, there are likely to be further calls for sophisticated and comprehensive information to support the easy control of such budgets by the public and their advocates.
- There are various government initiatives that are looking to support growth in assistive technology services provided by the retail and pharmacy sector. The Transforming Community Equipment Services initiative is now engaged in implementing a programme designed to “support the roll out of the retail model across England in 10 waves from September 2008 to March 2012”. This is in addition to supporting the engagement of high street retailers and pharmacies in the delivery of community equipment. The Assisted Living Innovation Platform, funded by the Technology Strategy Board, is also looking at the business models that will support the scale up of innovative telecare and telehealth services. Part of the wider delivery of these services, it is envisaged, will be through private purchase via high street retailers. With the entry of new market players information provision will shift becoming more available locally, perhaps in the form of engaging marketing material, but it is also likely to provoke an increased need for an independent, credible overview of the services and products on offer.

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<sup>29</sup> Shaping the future of care together, Department of Health, July 2009, <http://careandsupport.direct.gov.uk/greenpaper/>

<sup>30</sup> Local Authority Circular (LAC) (DH)(2009)1: Transforming Adult Social Care, March 2009

- **Personalisation:** Closely related to initiatives to find new ways to use resources and engage the public in spending their own resources on assistive technology services is the policy drive to deliver more personalised services. There have been a series of papers and initiatives to build the capacity of local services to deliver personalisation since January 2008 when a grant of more than £500m was announced<sup>31</sup> leading up to the Green Paper on social care and support in July 2009.

The rationale for this shift is partly to enable national government to take a step back from unpopular decisions about rationing resources, but also because the ability to control the shape of services proved popular with local councils and with service users. Using this approach, national government will not be responsible for implementation of services but will set out a framework within which local government will work out the needs of their local communities and how they will be met.

- Key elements of these initiatives will be service diversification, control of the care package by the recipient, greater support for self care and self-management and greater emphasis on brokerage services. Providing information tailored to individual need and various initiatives to support the development of universal, joined-up information and advice for all individuals and carers, including those who self-fund, is essential for supporting self care.
- In addition to information about NHS services, treatments and conditions being made available on the NHS Choices website, there are proposals to improve the quality of information provided by the third sector. The Information Standard is a certification scheme for health and social care information producers and run by the Department of Health. Those organisations that meet the criteria of The Information Standard will then be entitled to place a quality mark on their information materials so people searching for health and social care information can easily identify it as coming from a reliable, trustworthy source. The Information Standard mark aims to help people make these decisions with confidence because it offers reassurance that health and social care information carrying the mark is from a reliable source. The reason this was required was that research undertaken by the Department of Health found that information available to people varied greatly in terms of quality, accessibility and availability.
- In October 2008 the Department of Health published a report on information prescriptions which will be delivered by health and social care professionals to ensure people with long-term health or care needs receive information to help manage their condition. In April 2009 the government published “Working Together: Public Services On Your Side” which proposed that 15 million people with long-term conditions will be offered a personal care plan by December 2010 and for people eligible to receive council-funded support: “person centred planning and self-directed support to become mainstream, with individuals having choice and control over how best to meet their needs, including through routine access to telecare”.
- **Accessibility/ equality:** There are some indications that the campaigning to achieve the Disability Discrimination Acts (1995 and 2005)<sup>32</sup> is now shifting towards access to health and social care services and to relevant information. A greater demand for context- and format-relevant information for niche groups and those previously poorly catered for is put forward on a basis of rights as well as to support the self-care agenda.

<sup>31</sup> LAC (DH)(2008)1: Transforming adult social care, Department of Health, January 2008: [http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/LocalAuthorityCirculars/DH\\_081934](http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/LocalAuthorityCirculars/DH_081934)

<sup>32</sup> The DDA (2005) is relevant to employment, education, access to goods, facilities and services, buying or renting land or property and various functions of public bodies, for example issuing of licences. The Act requires public bodies to promote equality of opportunity for disabled people. It also allows the government to set minimum standards so that disabled people can use public transport easily.

An example is the All Party Parliamentary Group for Parkinson's disease (APPG) report 'Mind the Gap' published in July 2009 into access to health and social care services for people affected by Parkinson's disease. The report reveals major inequalities in access to information and services for people with Parkinson's and their families. Such a report is indicative of the logical shift of voluntary sector campaigning towards equal access to information.

- Such a campaign is also shaping up around digital exclusion for disabled and older people. In November 2009 the Consumer Expert Group published "Report into the use of the internet by disabled people: barriers and solutions"<sup>33</sup>, implementing a recommendation in the Government's Digital Britain Report. The report is intended to inform Government strategy, as well as work by the Consortium for the Promotion of Digital Participation and the Champion for Digital Inclusion, Martha Lane Fox. Issues discussed include the availability and affordability of access technology, accessibility in web design, and support for disabled people using the internet.

### **3.3 Conclusions about the changing market for AT information**

There will clearly be a significant increase in demand for information about assistive technologies, as a result of demographic changes and policy drivers and it is realistic to consider a 30-50% increase on current demand. For planning purposes the following issues were considered to be of particular relevance:

1. More people will be self-directing their support and will have some choice over how they use Personal Budgets and Direct Payments from their local authorities and more people will pay for equipment themselves. Consumers will increasingly expect assistive technology and related information to be presented in a similar way to mainstream consumer items, without the stigma that is associated with current products. This does not necessarily mean that the supplementary information required to ensure the consumer can make an informed choice will be irrelevant; just that the decision on what information is provided and how becomes more complex. It is in this context that user reviews of equipment may be particularly effective.
2. For information providers, they will need to have increasingly close relationships with manufacturers and retailers who will be partners in providing the information required by consumers to make informed choices. This will become particularly relevant as technology becomes more integrated and issues arise about interoperability and installation, repair and maintenance, etc.
3. Some products, particularly electronic assistive technologies, are increasingly recognised as being a part of a service response rather than stand-alone. The information provided about such products needs to reflect this shift.
4. In line with similar demands for information about mainstream technologies there will be pressure on manufacturers and retailers to enable comparison between equipment prices and services costs, making the market more transparent and competitive. However, this will be balanced by the reduced influence of the proposed information guide over mainstream manufacturers and retailers if technologies become more commonplace.
5. In keeping with the government strategy on information provision for healthcare, there is an ambition to raise awareness of clear national starting points for information seeking about assistive technology. These should enable individuals to make an informed choice through the provision of impartial information free from marketing bias. In recognition that there will be increasing numbers of people buying assistive technology privately or acquiring it through the use of Personal Budgets, such information provision should ideally signpost routes to relevant areas such as legal advice and funding options.

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<sup>33</sup> [http://www.culture.gov.uk/reference\\_library/publications/6378.aspx](http://www.culture.gov.uk/reference_library/publications/6378.aspx)

## 4 Developing a relevant AT information service

### 4.1 A guide to show the public what AT is available

Having mapped the existing situation in terms of the project scope, the state of information provision on assistive technologies and the predicted state of change in the market for information, the Alliance members set out to develop a blue-print for a comprehensive information guide that would meet current and future needs.

Having considered various options for a guide, including posters, leaflets and online, the Alliance members concluded that a website was the preferred solution as it had the potential to reach the most people in a cost-effective way. It was agreed that this website would not try to reproduce existing information but would contain answers to the key questions people have about equipment and link to other sources of information. Assist UK, DLF, FAST and Ricability will verify the information and ensure external links are to trusted sites.

It was also decided that the website would convey information in a visual way. This would make it adaptable for potential use in printed materials. A plain text version will also enable it to reach the widest possible audience.



Developing the concept of the website guide [www.allaboutequipment.org.uk](http://www.allaboutequipment.org.uk) required detailed agreement between Alliance members on the scope of the mapping exercise and the criteria for inclusion that would be required from external information providers. The criteria and the way in which they would be implemented will form the basis of discussions with partners in year three of the project. The following section is work in progress, setting out our initial learning and draft conclusions about criteria and the external information providers that might meet those criteria. These have been drawn up with reference to in-house practice by Alliance members and external benchmarks for good practice.

## 4.2 Quality information sources to populate the website guide

Alliance members conducted a review of comparable information sources /databases in order to address gaps and deficits in the provision of information by Alliance members in relation to a full range of assistive technology cluster areas.

This review enabled the development of a set of criteria for 'quality' that external organisations could demonstrate that they met, or were working towards meeting, in order to feature their databases on the website guide. It was recognised that these criteria represented a standard which may not be attainable by all external information providers due to lack of resources, capacity or demand, but which could set a target quality standard. Where possible the standards for inclusion on the website guide related to standards already agreed as appropriate for similar exercises, such as the Information Standard. For other issues, underpinning legal requirements and accepted good practice are outlined to provide the explicit standard. These standards are likely to be developed further over year three as discussions are held with external information providers. The following sections outline initial thinking towards the end of year two which has informed early development of the website guide ([www.allaboutequipment.org.uk](http://www.allaboutequipment.org.uk)).

There was a range of issues to be considered in relation to quality. From a review of the existing provision of information on assistive technology, the AT Alliance criteria for quality information providers were established as follows:

- independent and credible
- national
- regularly updated
- comprehensive and balanced
- evidence-based
- freely available
- accessible to a broad audience

### 4.2.1 Independent and credible

To define independence in relation to information provision the AT Alliance initially looked to the Department of Health's Information Standard.<sup>34</sup> The Standard is a certification scheme for health and social care information ([www.theinformationstandard.org](http://www.theinformationstandard.org)) providing a quality filter that helps people to identify reliable information. Organisations that meet the 'standard' are then entitled to use the quality mark, a recognisable symbol of quality and assurance. DLF is one of 39 founder organisations of the Information Standard. DLF's public websites 'Living made easy' and AskSARA display the kitemark.

The standard tests whether organisations have methods and systems to ensure that the information they produce for the public is accurate, impartial, balanced, based on the evidence, accessible and well written. In relation to links with sponsors and the private sector, the standard states<sup>35</sup>:

- Any conflict of interest is disclosed
- Any advertising is clearly identified

However, there is a need to clarify this in more detail due to the requirement outlined above for assistive technology information providers to work in close partnership with manufacturers and retailers to supply comprehensive information on assistive technology products.

Work with manufacturers and retailers will help to ensure information provision remains viable in the current funding context.

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<sup>34</sup> The DH Information Standard 2010

<sup>35</sup> The Information Standard Requirements for Applicants, Final Version 1.0, October 2009

Given the restrictions on public spending that are anticipated over the next five years, it is vital that all forms of income generation are used to ensure sustainability of quality information provision. Most AT information providers rely for the majority of their funding on state support and there are good reasons why state support should continue to be forthcoming:-

- The first is that quality information on assistive technology is required in order to enable people to manage their care and support and so contributes towards cost management of health and social care budgets by supporting preventative care.
- The second reason is that assistive technology is widely accepted as a 'failed market' in that statutory procurement and provision of assistive technology over the last four or five decades has bent the market completely out of shape. It has been recognised that private purchase and consumer-influenced purchasing has to be supported in order to rectify this and to rapidly develop a more consumer-responsive market. This growth and maturing of the market, and delivery of related information, has to be done working in partnership with manufacturers and retailers.

Comparable mainstream information services such as Which? have built up relationships with manufacturers and retailers that do not compromise their jealously guarded independence. It is relatively straightforward for this to be equally the case for assistive technology information providers. Whilst there will be a requirement for most information providers to develop arms-length sponsorship relationships with manufacturers, such relationships have to be carefully managed in order not to compromise the independence and credibility of both the information and the information provider's reputation.

- DLF has worked successfully with commercial sponsors from the AT industry to support the development of 'Living made easy'. As a member of the Information Standard, DLF has a clear Conflict of Interest statement on its accredited websites, which reads:

#### **Potential conflicts of interest**

##### **Our sponsors**

Certain ethical companies who support our aims have provided financial investment to develop and maintain 'Living made easy'. These sponsors obtain certain benefits from being a sponsor, for example, access to our training courses and advertising within the website. View a list of our sponsors.

All sponsor adverts are clearly labelled with "Advertisement" to distinguish them from DLF impartial advice. Adverts with moving or animated designs are not used.

Suppliers' sponsorship has no impact on the inclusion of products, how we rate their products, their position within any product listings or any other advantage over other suppliers.

Our sponsors are happy to support us in this way because they understand that it is our very impartiality that makes us of value to those who seek our advice.

##### **Our staff**

DLF staff work to agreed impartial procedures which govern how advice or products are added to our websites, and when the information is updated. Thus there is no scope for individual bias or preference in the updating or inclusion of product information.

- Assist UK also has a relationship with manufacturers whereby a section of membership is open to commercial organisations; some centres demonstrate a particular range of equipment which is supplied at no cost by manufacturers; and some DLCs also enable the sale of a range of equipment, including mobility equipment, directly from the centres. The Assist Standards for Centres require assessments offered by centres to include information on equipment from different manufacturers and that assessment is located away from selling.
- Ricability's quality and procedures manual says:

### **Who we accept funding from**

Ricability jealously guards its independence. The risk is not that anyone could in practice influence our judgement but that a cynical public may view as suspicious any close relationship with organisations whose products or services we review. All commissions have to be within our remit and be in the consumer interest, even if this is only likely to be in the long term.

We have developed a series of guidelines about sources of funding. They are reviewed from time to time by Trustees. In doing so we separate information for consumers and privately commissioned work.

### **Information for consumers**

Obviously our first responsibility is to consumers. Generally acceptable sources of funding are:

- Government departments (providing they do not retain editorial control)
- Fund-giving charities
- Trade associations
- Trusts set up by companies, but which are independently controlled
- Consortiums of manufacturers (i.e. where they all contribute to the project in an equitable manner)

We do not accept funding from

- A manufacturer whose products are under test (eg The Ricability guide to stairlifts, funded by Stannah)
- Pressure groups who are interested only in research that proves a certain point, where the association would jeopardise perceptions of our independence.

### **Privately commissioned work**

The result of this work is not usually in the public domain. Typically manufacturers may commission us to help with the development of a new product or the development of an existing one. This work is acceptable as long as we consider it to be in the long-term consumer interest. However

- If the work is commissioned by a manufacturer whose products or services we may test at a future date it needs to be made clear that this private research will have no effect on any research carried out in future – findings will be entirely based on what this later research shows.
- Claims made about the product ('developed with Ricability' 'Approved by Ricability') need to be sanctioned and controlled by us. While we have no objection to truthful claims any claims must realistically represent results and make clear any limitations of the research (eg 'easy for partially sighted people to use' rather than 'easy to use').

A key issue in relation to the credibility of information is to establish the legal framework of good practice in information provision. This also sets some boundaries about what can be stated in comparative reviews of products. This issue is managed by AT Alliance members as follows:

- Assist UK hold professional indemnity, trustee indemnity cover and employer public liability insurance centrally but does not cover member centres. Assist UK also feature a disclaimer on their website.
- Ricability's draft reports are verified by a second researcher, sent out widely for comment and are governed by strict data logging and information tracking requirements. They are also read by a libel lawyer who will identify any risk prone statements and will demand reassurance that there is the appropriate evidence to support them.
- DLF has a disclaimer on all its websites, the text of which is included in Appendix 3.

Professional indemnity insurance for information providers

- There appear to be few explicit issues in relation to securing professional indemnity insurance for assistive technology information providers who use and quote the source of externally provided information, for example from manufacturers. The choice of what to buy is that of the customer, who has consumer rights and the manufacturers' guarantee regarding the product itself.
- When providing advice and guidance to the public on which of a range or type of products to purchase, organisations employing practitioners need to be covered by Professional Indemnity Insurance and Public Liability Insurance in the same way as any independent practitioner .

Disclaimers are one mechanism by which information providers seek to manage the legal and financial impact of litigation in relation to information provision. Although publishing a disclaimer on a website is a relatively widespread practice, there are limits on its effect set by law and the courts.

Wikipedia Tort Law states:

“Under UK law, the validity of disclaimers is significantly limited by the Unfair Contract Terms Act 1977. By virtue of the Act, a business cannot use a contract term or a notice to exclude or restrict its liability for negligence causing death or personal injury. In the case of other loss or damage, a disclaimer will only be effective so long as it is reasonable in all the circumstances. “

Disclaimers may be useful as an indicator of potential risk to the customer – but they need to be clearly stated and in accessible formats.

### **Criteria required from external websites for being independent and credible:**

To qualify for inclusion on the proposed [www.allaboutequipment.org.uk](http://www.allaboutequipment.org.uk) website guide, external organisations providing information on assistive technology will be required to:

- Comply with the Information Standard in relation to
  - advertising being clearly marked to differentiate it from other content
  - the publishing of a conflict of interest statement.(However, we will not require a website to be accredited by the Information Standard at this point as this is a new scheme with few members, but we will encourage organisations to which we link to, to join the scheme).
- Publish their sponsorship rules and note their funding sources.
- Note the processes by which products are included within the organisation's information provision activity, such as database population or research scoping. This is particularly relevant for organisations who sell their own products, such as the RNIB and RNID.

- Note the process by which product information is drafted, note the organisation's reliance on and process for checking manufacturers' information, including any independent evaluation of manufacturer information.
- Those organisations that include advice and guidance on their website, over and above information about available equipment, to note the process by which they manage quality and public and professional liability.

#### 4.2.2 National information provider

It would be unfeasible to link to a comprehensive range of local information providers through a website guide and also be able to ensure the quality of the information provided by those providers. The aim is to link to a smaller number of 'national' providers who can provide information about technology clusters not covered or only partially covered, by Alliance members. Where no such national information provider exists, this will be noted and a good regional provider of information may be signposted to on the basis that this provides a template for the kinds of equipment services that should be available nationally.

The definition of 'national' of course means more than the immediate geographical location of the information provider organisation. With online information, it is effectively globally accessible. However, in this context of AT information, we would define it as information that is accessible wherever one is in the UK and relating to provision of equipment that is available across the UK wherever possible. Where the information relates to local equipment providers, for example of adapted vehicles, this must be noted on the website guide to alert the public to these geographical restrictions.

#### Criteria required from external websites for being a "national" information provider:-

- Information that is accessible wherever one is in the UK and relating to provision of equipment that is available across the UK wherever possible.
- Where the information relates to local equipment providers, for example of adapted vehicles, this must be noted on the website guide to alert the public to these geographical restrictions.
- In practice service provision systems are often different in Scotland and Northern Ireland from those provided in England and Wales. Where this is so there should be a requirement to show what these different systems are; any national provider should cover all four countries of the UK.

#### 4.2.3 Regularly updated

The guidance on updates in the Information Standard is that<sup>36</sup>:

Each information product should clearly display a:

- publication date; the date on which the document was first published:
- review date; the date by which your document will be reviewed and updated if appropriate.

Good practice includes:

- Recording the publication and review dates for each information product in your archive.
- Implementing a process to ensure information products are reviewed by the stated date. This should include sufficient time to conduct new searches, analyse any new evidence and update the product accordingly.
- DLF has practice guidelines which state that advice in its accredited materials will be reviewed and updated every two years. Product and supplier information is not included in the scope of the Information Standard but DLF has a process to update these over the course of every two years also.

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<sup>36</sup> The Information Standard Requirements for Applicants, Final Version 1.0, October 2009

- DLF's web-based self-service system also allows suppliers to update details such as pricing, contact details and product availability themselves to help keep the information up-to-date.
- Ricability is setting up a system whereby contact information (names, addresses, telephone, fax, text, email and website) is systematically checked every six months. It is generally not possible to do this more widely where retests of a product or new assessments of a service would be needed.
- FAST conducts an annual exercise of contacting assistive technology researchers to secure update information. If three emails are unanswered and desk research shows no reason for this, such as change of address or contact information, then the text 'no information available' is entered in the relevant field. Projects finished more than three years previously are archived, though still publicly accessible, and it is noted that the relevant information is not updated. However, this does not address the need to secure updated contact information. This information is searched for specifically on an ad hoc basis when time and funding allows.

This is very much a matter of resource availability and Alliance members felt it may be difficult to set specific standards with regards to timeframes within which information should be updated.

#### **Criteria required from external websites for regular updates:-**

- It was agreed that the criteria for external organisations would be inline with the Information Standard above e.g.
  - Each information product should clearly display a:
    - publication date; the date on which the document was first published:
    - review date; the date by which your document will be reviewed and updated if appropriate.

#### **4.2.4 Comprehensive and balanced**

This criterion was particularly hard to define. It was agreed that there were two ways in which one might define 'comprehensive', the first in relation to the scope across technology cluster areas and across the range of products (horizontal), the second in relation to the depth of information and relevance of the information provided for each product reviewed (vertical).

**Horizontal scope:** It was agreed that there are probably three levels at which the scope of information about assistive technology is produced:

- **'full' review** which identifies 90-95% of products available in the UK (or those which are not effectively duplicates or re-brands of existing products)
- **'type' reviews** which look at typical features of different types of products across a full range
- **'taster' reviews** that give a flavour of a selected group of products, for example, new items, items that meet specific needs, items available from particular suppliers and services.

The definition of 'comprehensive' also depended on the stated scope of the information provided. It was agreed that as long as the scope of the information provided was clearly stated, ideally with signposting to information providing complementary or more comprehensive overview, this would be an acceptable criteria.

**Vertical scope:** There is a range of information that can be provided about any device, not only in terms of how it functions, but also in relation to how it works with other equipment and in terms of its use for people with particular impairments, task requirements or environmental challenges. There are restrictions on what information can be provided due to the reliance on information provided by manufacturers as noted above, the lack of standardisation in information provision by manufacturers and the lack of evaluation information provided at a national level.

There is also a range of information, which we discuss below, that relates to the product's robustness and effectiveness in meeting people's needs over time. Alliance members acknowledge that this information is required but recognise that it is not currently available without in-depth research.

DLF includes the following information on products as a matter of course:

- Name
  - Description (written by DLF's occupational therapists)
  - Guide price (where available; retail price excluding VAT)
  - Features
  - Options
  - Manufacturer details (if known)
  - Dimensions (broken down into 'Critical dimensions' and 'Other dimensions' – 'Critical dimensions' are those dimensions that DLF's team of Occupational Therapists consider essential for informed choices to be made)
  - Supplier details – contact information, trade association membership, product name, price, additional information (e.g. show room access, online shop, home demos and mail order)
  - Videoclips (where available)
  - User manuals (where available)
  - User comments/reviews (user-generated content)
- For some categories, e.g. telecare, DLF includes information on items that are required for that product to work or are compatible with that product.
  - The information that should be included is regularly reviewed by DLF's staff to ensure it meets user needs and new fields are added to DLF's database when required.

Ricability establishes the range of information to be provided on an ad hoc basis. This is generally defined quite widely, but depends on the subject being covered.

- Where products have been tested apart from test results and product information (which are usually very detailed), information will include specific brand and model name, typical retail prices, things to consider and look for, tips on use (where it would be useful to provide these), manufacturers' details and pictures of the product itself.
- All Ricability reports include information on how to obtain the products through private and statutory sources, often with practical information on how this is done and what might be involved
- All Ricability reports include a directory of further sources of information and advice
- Most include details of the various ways of finding funds to pay for the product.

#### **Criteria required from external websites for providing comprehensive information:-**

These will state the scope of the information provided, ideally in relation to a broadly used categorisation approach:

- If the information provided does not constitute a comprehensive range, the organisation will signpost to more comprehensive overviews of the stated area.
- The organisation will state which class of information is provided, full, type or taster, horizontally across the range of technologies.
- Must state the vertical depth of data provided as standard for products and services and set out the process by which the depth and classes of data were decided upon.

It was noted that an activity for year three of the project was to discuss with external information providers what information is provided as 'standard' for different ranges of equipment.

#### 4.2.5 Evidence-based

A requirement of the Information Standard is that information is 'evidence-based'. This is problematic to some degree for assistive technology information providers as there is a lack of evaluation information across the range of devices available to meet common requirements. DLF does include references, where available, within its accredited advice to meet the Information Standard. The relative lack of evaluation information arises from the fact that there is currently no national programme to make independent evaluation of an appropriate range of assistive technology available to the public and to professional intermediaries.

Such evaluation programmes are carried out in other European countries but evaluation programmes that cover a comprehensive range of products and keep the information up to date are rare. These have existed in the Nordic countries and, for a range of products, were carried out by the Medical Devices Agency in this country before its transformation into the MHRA. The main barrier to such a programme is cost and no obvious source for such funding. Ricability is investigating the feasibility of such a programme being organised on an international and cost sharing basis.

Though technical features and safety need to be assessed as part of an evaluation, they are only part of the information required. Good design and usability of features are often deciding factors in whether someone will purchase or continue to use a device and these features also need to be captured in any evaluation.

This lack of an evidence base and subsequent guidance is an issue that affects the entire sector and can be seen by the lack of clarity on assistive technology provision within care pathways, national standards frameworks, within education curricula, etc. As a consequence disabled people, older people and their families and carers are not supported to make decisions about assistive technology. The recent online DLF survey of parents with disabled children found that 50% of parents responding to the survey did not think that the information they had found was sufficient to make an informed choice about the best product for their child.

Again there is a strong reliance on information provided by manufacturers about the effectiveness of their products. The primary requirement, once people have established that a range of devices or services are likely to meet their needs, is to identify which particular device would best do so. However as noted above, this is problematic for information providers given the lack of specific guidance or even agreed processes by which one can make that assessment.

Whilst Alliance members would not suggest that it would be possible to develop guidance for every individual's particular circumstance, given the lack of evaluation data this has resulted in a lack of generic guidance available to support the purchase of relatively straightforward equipment for the large proportion of consumers for whom such a purchase would carry little risk. Some of this knowledge has been built up by practitioners and some is available within the literature, but this is yet to be translated into guidance and advice that can be made readily available to the public.

Despite these problems DLF has provided an online decision support tool, AskSARA, which covers a range of relatively straightforward equipment. One other organisation, ADL Smartcare, has also developed such a tool. Both tools are informed by expert consensus, with both drawing on panels of experienced practitioners to decide on issues such as effectiveness of specific devices and also on issues of risk in relation to the provision of guidance to members of the public. A national version of AskSARA is available free for public use at [www.asksara.org.uk](http://www.asksara.org.uk). A number of local authorities have customised versions of these tools to provide additional local information for their residents.

Ricability has searchable databases on cars and wheelchair accessible vehicles, powered wheelchairs and scooters which allow people to draw up a shortlist of specific models based on their own requirements. These are based on descriptive data and measurements rather than evaluation.

Without evaluation information and an evidence base of what works, information providers are restricted in what they can say to guide their audiences towards more effective and attractive products. It is possible that user reviews may be one way of delivering information about 'what will work for me' to the public and indirectly to practitioners. Further work to examine and support the use of user reviews will be undertaken in year three.

#### **Criteria required from external websites for providing evidence based information:**

- Given the lack of a comprehensive evidence base we would ask external websites to:
  - link to evidence where available
  - include the option for individuals to add reviews and comments
  - evaluate the effectiveness of products through use of a transparently appointed and structured panel of experts, including practitioners, users and service providers

#### **4.2.6 Free to the public and practitioners**

As noted above, information provision must be substantially funded by the state and also by sponsorship in order to be free at the point of delivery to the public and to practitioners. There are, of course, costs to the public relating to the use of the internet, the phone, downloading of information to hard copy and attending training or confidence building courses. However Alliance members felt that it was not appropriate to signpost to information that required payment at the point of delivery to the public.

#### **Criteria required from external websites for providing free information:**

- Must be free at the point of delivery to the public (excluding related costs for access by internet, phone, etc.)

#### **4.2.7 Accessible to a broad audience**

There are several ways to define accessibility and section 2.6 above looks at some of the issues in relation to providing information in a range of formats to maximise accessibility and inclusion. In terms of criteria for accessibility and in view of the challenges experienced by Alliance members themselves, Alliance members felt that it would be reasonable to ask external information providers to comply with the following criteria or show that they are making reasonable steps towards complying with the criteria:

#### **Criteria required from external websites for accessibility of information:**

- Websites should follow W3C accessibility guidelines where possible.
  - Information prepared for screen display should display in different ways either by changing browser settings or through accessibility options on the website itself, the latter being the preferred option. Such information must be compatible with screen readers.
  - At this initial stage we would ask organisations to state whether user testing of online material has been done or not.
- Printed and downloadable text
  - Text that can be downloaded should be 'printer friendly'. It should print out in an easy to read format; short lines, clear layout, clear headings and be free of extraneous information. Font type and size should follow RNIB guidelines<sup>37</sup>.

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<sup>37</sup> RNIB [http://www.mib.org.uk/professionals/accessibleinformation/Pages/see\\_it\\_right.aspx](http://www.mib.org.uk/professionals/accessibleinformation/Pages/see_it_right.aspx)

Use of pale colours should be avoided, and any illustrations should fit into the text neatly. If it is necessary to use more than one page the page break should be in a logical position and the pages be numbered. It should be obvious how to print the page and this should be easy to do. It should work with all printers and from both Apple and personal computers.

- Information should be available for printing in larger formats and as word only (without illustrations).
- Information should also be made available in other formats such as audio. (This can be done through text by using commonly available text to speech software, but better quality and more sophisticated indexing and navigation is likely to be available by producing separate sound files which can be downloaded or listened to directly from the website).
- Languages
  - There are a large number of languages spoken by significant numbers of UK residents however resources rarely allow national level information providers to provide their information in these other languages. The Alliance is not in a position to set any criteria for multiple language provision.

#### **4.2.8 Mapping of external AT information providers**

Consideration of gaps or deficits in the overall provision of AT information by Alliance Members is a key factor in mapping external information providers. The extent to which these gaps and deficits may be addressed by external information providers is considered in Appendix 1.

To assess the manner in which organisations are currently approaching the information quality criteria discussed above, a range of independent, online AT product databases, considered to be credible by the Alliance, have been reviewed. The selection included both general and specialist organisations, with and without an online shop. Analysis, which is ongoing, includes a review of any information relating to the quality criteria described above, plus further information mapping:

- The web search process
- Product comparison facility
- Provision of 'related information'
- Evaluation information
- User reviews and user forum
- Product instruction sheets to download
- Accessories
- VAT exemption

Already apparent are:

- Variations in organisations' approach to indicating how they maintain their independence and impartiality.
- Differing approaches to providing support and guidance to enable website users to select products.
- An increasing emphasis on user reviews to provide evaluation information

### **4.3 Information related to the purchase, acquisition and use of assistive technologies**

There appears to be a significant requirement to understand the funding and legal context relating to assistive technology provision and use. It is proposed that this 'equipment related' information is of significant relevance to users of AT. We would propose that this information includes:

- Access to maintenance and support services,
- Insurance and financing options,
- Legal rights in relation to purchasing of new and previously used equipment

- Legal responsibilities for organisations and individuals who act as an employer of care staff and personal assistants who use assistive technology as part of their caring duties,
- Legal rights as a recipient of care services with rights and responsibility for the use of equipment shared with care providers and care staff.

#### **4.3.1 Access to maintenance and support services**

For much of the more sophisticated electronic assistive technologies to support communication or rehabilitation, but also in relation to lower technology interventions including stairlifts, it is often the service element which is most relevant. Many forms of electronic assistive technologies, such as telecare, communication aids, environmental controls and even some of the more complex electronically enabled mobility equipment require an on-going service package. Some of this is in response to repair and maintenance requirements and some to ensure interoperability with other electronic devices or to facilitate a new range of tasks. Some is to respond to changing personal needs and for someone with a communication aid this can be a complex interaction requiring knowledge of learning and social environments.

These 'service and support elements' are not currently covered on the DLF 'made easy' section and it would be difficult to do so while the consumer-influenced and private purchase market is developing in this area and services are in a state of flux. Ricability has covered such issues in the past by carrying out surveys of consumers, by collecting comparative information from manufacturers (for example on servicing and repair facilities). There are no technical reasons why more such evaluations should not be carried out, but they would need funding.

At the moment the 'elements' of the service that need to be considered (beyond the box on the wall, the complex switch or free standing item) are not clear for the public, nor is it clear who will provide the back office services or whether there are alternatives to buying a particular support service, such as getting a local garage to change a wheelchair tyre, contracting an independent speech and language therapist to deliver support, or getting friends and family to provide response and monitoring services.

Currently this information is not easily available<sup>38</sup> which serves to make the service element invisible and continues the preconception in the minds of many purchasers that up-front costs for a device are the most significant issue to consider, when this is often not the case.

There are also no generic service standards<sup>39</sup> across AT but the BHTA does operate a Code of Practice (that covers the element of selling).

#### **4.3.2 Information on eligibility, financing and insurance**

Local Authority social services departments operate Fair Access to Care policies which set levels of eligibility for council services that can result in many people not being eligible, either through level of income or level of need, to have a home assessment to identify their assistive technology needs, or to access relevant information about equipment or the provision or loan of such equipment. NHS Choices notes that "There are no national eligibility criteria for community care services. Each local authority sets its own criteria, and so there are variations around the country. However, the Department of Health has issued guidance on fair access to care services, setting out the framework for determining eligibility that local authorities should consider when setting their criteria." This guidance is under review.

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<sup>38</sup> An example of the information available to support private purchase of telecare which was previously downloadable from Kent County Council's website appears not to be available at 10 March 2010.

<sup>39</sup> Assistive Technology: Standards for Service Provision, FAST, 2005 <http://www.fastuk.org/>

This variation makes it difficult to provide advice on a national level about eligibility beyond identifying the process or linking to NHS Choices and Directgov<sup>40</sup> that do so to some degree. Further work will be undertaken in year three to establish the most effective way to provide useful generic guidance or to link to such guidance, including looking at the developing social care model of self-directed support and the implications of using Personal Budgets to purchase equipment.

Ricability has identified gaps in information about financing options and about insurance in that there is no independent information available for consumers in relation to AT (for example, insurance for some large items of equipment and where it is used by staff providing personal care in the home or workplace).

### 4.3.3 Information on legal rights and responsibilities

There is a range of information in relation to legal rights and responsibilities relating to assistive technology that Alliance members identified as not being available to the public in a comprehensive or easily accessible format. The information requirements were proposed as:

- Legal rights in relation to the purchase of new and previously used equipment,
- Legal obligations as an employer of care staff and personal assistants who use assistive technology as part of their caring duties,
- Legal rights as a recipient of care services with rights and responsibility for the use of equipment shared with care providers and care staff.

Alliance members provide the following information in relation to these issues:

- Ricability has included a guide to legal consumer rights on its website, and this is being extended to answer a set of frequently asked questions, including coverage of second hand products. This information is being written by a consumer lawyer and will be freely available to all.
- DLF provides information on how to make complaints about assistive technology or reporting unsafe equipment<sup>41</sup>.

A mapping of information providers who provide legal and funding information relating to assistive technology will be finalised in year three. Discussions will then be held with these information providers to establish whether they would wish to be included in the website guide and to discuss any relevant quality criteria.

## 4.4 Additional information needed to sustain the use of technology in the long term

There is a range of information which would enable users to sustain their use of technology over the long term, which is usually not available from manufacturers or through testing. Planning how to provide this information will be the focus for future development work by Alliance members.

- life cycle costs
- maintenance requirements
- inter-operability<sup>42</sup> and adjustability
- safety and risk

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<sup>40</sup> Directgov: <http://www.direct.gov.uk/> (accessed March 2010)

<sup>41</sup> Disabled Living Foundation's 'Living made easy': <http://www.livingmadeeasy.org.uk/>

<sup>42</sup> *Interoperability*. Particularly relevant to electronic AT. Denotes system where different application functions are able to use shared platform or data in a consistent way. The benefit is that applications can interact with each other and create greater efficiencies by sharing resources across multiple systems. Also relevant to different low tech technologies that share common systems such as mounting systems, etc.

## 4.5 Conclusions about mapping the information environment

1. In order to provide coherent and comprehensive information provision on assistive technology, Alliance members recognised the need to work collaboratively with other organisations providing complementary and related information.
2. In order to maintain the quality of information that would assist users to find the most appropriate technologies both Alliance members and other information providers need to have a clear set of quality standards to aim for and which will form the basis of any collaborative agreement for the joint provision of information services.
3. Setting out such quality criteria and practices has enabled Alliance members to establish the work required for their own organisations to meet such quality standards.
4. These aims for quality criteria are set out in the context of a challenging funding situation. It is recognised by Alliance members that achieving such quality standards will not happen overnight.
5. The lack of existing benchmarks and approaches to gathering data make it particularly difficult to judge the appropriate scope and quality standards for information. Reference has been made where possible to external benchmarks and to established in-house practice. Setting out these standards is the first step towards reaching consensus on good practice across a wide range of AT information providers.

## 5 Conclusions

### 5.1 AT Alliance

Collaborative work in the first two years by AT Alliance members included research, comparing databases for equipment, sharing stands at exhibitions and conferences, raising awareness of each organisation through their extensive networks, sharing learning in their specialist areas and working directly with equipment manufacturers and suppliers. The AT Alliance member organisations plan to develop an ongoing collaborative communications strategy.

There have been many ideas shared and acted upon which have influenced other projects. National policy developments such as Personalisation and Transforming Community Equipment Services (TCES) have been reflected in the thinking which, together with the roll out of policies from the new coalition government, will impact on work in Year 3 and beyond.

As a result of this project the AT Alliance has established its own website ([www.at-alliance.org.uk](http://www.at-alliance.org.uk)) which will showcase the collaborative work of the Alliance member organisations, their work on the Information Network for the Future project, the project reports and findings, and the website guide [www.allaboutequipment.org.uk](http://www.allaboutequipment.org.uk).

### 5.2 Actions for year 3

Work in year three of the project will include user-testing and promoting the new website guide and further research and evaluation culminating in a final project report to disseminate the findings, a public event and the official launch of the website guide.

The Alliance will look at ways to strengthen links to national level information providers such as Directgov and NHS Choices, and at how to achieve the effective cascade of information from national to local level, for example through Citizens Advice centres and Dial UK.

Further exploration will be undertaken on how to strengthen the role of GPs and pharmacists as assistive technology information sources and at how to support other third sector organisations in providing more information on assistive technology, including a longer term awareness campaign.

The Alliance will promote quality standards that help consumers differentiate good quality information from poor, including the DH Information Standard kitemark. There is a need for further development of information sharing and the potential for horizontal links between different forums of consumers and users of services.

On behalf of the Alliance, DLF will continue to host and update the website guide, and Alliance members will look at the current free online options for the translation of information into other languages, the quality of translation, current language limitations and the need for user-testing for accessibility.

AT Alliance members will work with

- existing database providers on their potential to be included in the website guide
- the commercial and retail sectors to influence market change
- user-led organisations to improve access to information and equipment
- other organisations to develop new databases for technology clusters not currently covered
- organisations providing information on the use of Personal Budgets and Direct Payments

In addition, further work is required to identify a standard minimum set of data for items of equipment to enable consumers to make more informed choices, and to assemble information on the range of equipment on display at the various Disabled Living Centres and Independent Living Centres around the country and how that information is disseminated in the local area. However these last two areas are outside the scope of this project.

**This report highlights the importance of this area of research and the need for further funding for the work identified and in particular for an awareness raising campaign.**

**Access to timely information will empower people to help themselves to stay healthy and active for longer. As well as benefiting individuals this will save money in the NHS and social services by reducing unnecessary loss of independence and falls resulting in hospital admissions, including the consequent need for increased levels of health care and support.**

Government spending cuts over the next few years will result in significant changes to health and social care services and disability benefits and in the current economic climate it is unlikely that central Government will undertake an awareness raising campaign in this area.

However, key players in the AT industry might consider coming together to fund such a campaign. This is common practice within other sectors where a number of organisations campaign together to achieve more than they can individually. For example, in the voluntary sector many charities have supported the Remember a Charity campaign to raise awareness of legacy giving, while the public sector and voluntary sector have come together in the Changing Places campaign for improved access to toilets suitable for people with profound and multiple learning disabilities, as well as other serious impairments such as spinal injuries, muscular dystrophy, multiple sclerosis or an acquired brain injury. A number of mental health charities came together to campaign for access to talking therapies on the NHS in the 'We Need To Talk' campaign, while Make Poverty History saw a large number of organisations come together to campaign for an end to extreme poverty. The AT Alliance will discuss this idea with key contacts in the AT industry over the next 12 months.



## Appendix 1 Gaps and deficits in free, online AT database information

Featuring commercially available AT by AT Alliance members and potential links with external database partners to provide comprehensive database coverage

\*'Gap' indicates approx less than 5% coverage, 'Deficit' indicates less than 50% coverage

\*\* free information also available from AT Alliance members through phone-line, factsheets, booklets and demonstration

	AT for lifelong learning and employment - ICT	Communication aids (speech)	AT for sensory impairment	Electronic AT: telecare, telehealth, environmental controls and automated homes	Adapted housing, built environment	AT for daily living and social care	Healthcare at home (stoma care, continence, home therapies, etc)	Prosthetics and orthotics	AT for cognitive support (AT for dementia and learning disabilities)	AT for recreation and exercise	Robotics and virtual reality	AT for driving, public transport and navigating the external environment	Electronic AT integration and controls	AT for mobility, posture and seating
Living made easy	Deficit: covers some AT to access ICT for children	Deficit: covers some communication aids for children	Gap	Deficit: covers telecare. Also some telehealth and environmental controls but not comprehensively	Gap	Covered	Deficit: covers pressure relief but not continence and home nursing equipment comprehensively	Gap	Deficit: has some but not comprehensive	Deficit: covers some recreation activities for children, doesn't cover sports equipment comprehensively	Gap	Deficit, covers some transport equipment for children but not wheelchairs and scooters for adults	Gap	Deficit: doesn't cover posture systems for adults
Ricability												Deficit: only covers cars, electric wheelchairs and scooters		
Existing free, online database providers	Emptech	ACE Centre (due Sept 2010)	RNIB, RNID	None identified	None identified		None identified	None identified	ATDementia	None identified	None identified	None identified	None identified	None identified
Potential partners				Alvolution, Assistech	Centre for Accessible Environments, Building Research Establishment, RIBA, Habinteg		Long Term Conditions Alliance, Department of Health	British Association of Prosthetists and Orthotists		Inclusive Fitness Initiative, Sport England	UK Network for Rehab and Assistive Robotics	Department for Transport, Forum of Mobility Centres, TfL, Blue Badge Network	Assistech	Posture and Mobility Group

## Appendix 2 Relevant Policy Papers 2006-9

Date	Policy	Implications for equipment provision, information and training
March 2006	Transforming Community Equipment Services (TCES)	<p>Driven by the DH's Care Services Efficiency Delivery team, this new model of community equipment delivery puts users and carers at its heart.</p> <p>The model is a retail solution and proposes that state bodies issue users and carers, where there is an assessed need, with a 'prescription' that can be exchanged for free equipment at an approved/accredited retailer. TCEWS also highlights the necessity for staff at accredited retailers to reach a certain level of competence in order for those stores to be accredited.</p>
March 2006	Securing Good Care for Older People: Taking a long-term view	A review undertaken by Sir Derek Wanless and commissioned by the King's Fund that sought to determine how much should be spent on social care for older people in England over the next 20 years and what funding arrangements need to be in place to ensure that this money is available and will produce high-quality outcomes.
August 2006	DH self-assessment pilots	11 Local Authorities are selected to run pilots allowing people with long term health and social care needs to self assess their need for home care and equipment.
June 2007	Assistive Technology Workforce Development	A feasibility study for development of an AT workforce strategy.
December 2007	Putting People First: A Shared Vision and Commitment to the Transformation of Adult Social Care	Sets out the shared aims and values that will guide the transformation of adult social care. Recognises that the sector will work across agendas with users and carers to transform people's experience of local support and services.
February 2008	Lifetime Homes, Lifetime Neighbourhoods: A National Strategy for Housing in an Ageing Society	Strategy to help the ageing population stay independent by providing mainstream homes that adapt as people age. Provides a foundation from which to incorporate telecare and telehealth services.
May 2008	Whole Systems Demonstrator programme and network	Department of Health funded randomised controlled trial of telecare at three sites – Cornwall, Kent and Newham. Designed to provide an evidence base for the use of telecare to support people living with long term conditions.
June 2008	Common Core Principles to Support Self Care: a guide to support implementation	Developed by Skills for Health and Skills for Care, the principles capture best practice in order to support service reform and promote choice, control, independence and the participation of people who use services.

<b>Date</b>	<b>Policy</b>	<b>Implications for equipment provision, information and training</b>
February 2009	National Dementia Strategy	Strategy endorses the role of AT, specifically telecare, in supporting people with dementia.
April 2009	Working Together: Public Services on Your Side	Government proposals for 15 million people with long term conditions to be offered a personal care plan by December 2010 which could include access to telecare.

## Appendix 3 Disclaimer on DLF websites

“While we do endeavour to ensure that the information contained in this Website (including in the Database and/or the Factsheets) is accurate, appropriate and up-to-date, you should note that:

- since much of the content of the Database is provided by the producers, suppliers or distributors of the assistive technology featured, we cannot and do not undertake to monitor every item on the Database;
- we make no representations, warranties or endorsements about either the information included in this Website or its accuracy (including in relation to any opinions or advice given whether in the Factsheets or otherwise), nor about any assistive technology featured in the Database; and
- anything on this Website is for information purposes only and does not constitute investment advice, legal or professional advice and should not be treated as a substitute for the advice of your own doctor or any other health care professional. You should always consult your own GP if you are in any way concerned about your health or the health of another person.
- The information that you receive on this website is NOT a substitute for individual assessment. We recommend that you arrange an assessment with an occupational therapist before purchasing any daily living equipment that may affect your balance, mobility, posture, pressure care, ability to summon help, or general safety. You need to consider if the equipment will work as you intend, when you are in your home environment. Ideally you should trial the equipment at home before you purchase.
- Although we cannot guarantee the prompt editing or removal of any inappropriate or inaccurate content, if you find any content that is inaccurate or inappropriate then please Contact Us.

While we use virus checkers to check the content of the Website, we are unable to guarantee that is virus and/or error free. You should always check any content before downloading. Any content is downloaded by you from the Website (including from the Database) at your own risk, and on the basis that you will be solely responsible for any damage to your computer system or loss of data that result from the download of such content.

**IMPORTANT: Please note that you are solely responsible for any decisions you take based on the information contained in the Website.**

**On the basis that you are accessing this Website for business and commercial purposes, and/or our status as a charity, you agree that, unless we specifically state otherwise, we provide this Website (including the Database and the Factsheets) to you without any conditions, warranties, or guarantees, whether express or implied, including but not limited to any implied warranties or conditions as to the satisfactory quality or fitness for a particular purpose, which are expressly excluded to the extent permitted by law.”**

## Appendix 4 Questionnaire to elicit feedback on equipment information used at Naidex in 2009



An Alliance of four Assistive Technology information charities - DLF, Assist-UK, Ricability and FAST- are undertaking a Department of Health funded project to develop a future AT Information Network.

They would appreciate the help of NAIDEX attendees in completing this brief questionnaire:-

### 1. In what capacity are you attending NAIDEX?

AT trade  health professional  carer/parent  individual for own need   
 Other? .....

### 2. Have you heard of? DLF Assist-UK Ricability FAST

Ever contacted? "  "  "  "

### 3. How do you rate your experience in obtaining AT equipment information ?

From:-	happy	satisfied	disappointed	no experience
Exhibitions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Internet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Retailers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Living Centres	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Health professionals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Media	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other? .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

### 4. What do you think are the main gaps in providing INFORMATION about AT equipment? (Tick all applicable and please circle the one you feel most strongly about.)

- Guide(s) to obtaining equipment info.  Independent equipment reviews
- 2<sup>nd</sup> hand equipment  Fitting and servicing  Assessments  Renting
- Insurance issues  Research & development  Quality mark for information
- Staff training  Consumer rights / the law
- Other? .....

### 5. Any other comments or suggestions? ( e.g. better signposting by GPs, Pharmacies )

.....  
 .....