

The future for personalisation? Service users, carers and digital engagement

A report commissioned by IRISS from Shirley Ayres, Aspire Knowledge

August 2011

Comment on this report

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1. The Authors

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2. Introduction

Carers and people who use services require information about the available sources of support; professionals need information about service providers to support effective practice in commissioning services. In recent years, social media has made an impact on the way much of the population communicates, collaborates and shares knowledge.

Knowledge management, transfer, sharing and exchange feature prominently in [Changing Lives](#) (Scottish Government, 2006), while the personalisation agenda also relies heavily on the availability of knowledge and information.

This study examines the relevance of social media to the development of personalised social care in general, and to self-directed support in particular. The focus of the report is the UK but, given the global nature of web-based communication, it does include some international initiatives.

It should be noted that in such a rapidly changing subject, a report such as this cannot claim to be comprehensive. Rather it provides an overview and highlights a selection of initiatives that demonstrate the diversity of approaches. The aim is to promote better understanding and stimulate further activity and discussion.

2.1. Internet and society

Over the last fifteen years or so the internet and the world wide web have become firmly established in the mainstream of everyday life. According to the [Office for National Statistics \(2010\)](#), 30.1 million adults in the UK (60 per cent) accessed the internet every day or almost every day in 2010. This is nearly double the the 2006 estimate of 16.5 million.

The number of adults who had never accessed the internet in 2010 decreased to 9.2 million, from 10.2 million in 2009. The number of people who used a mobile device such as a laptop or mobile phone to access the internet away from the home or workplace increased from 40% to 45% between 2009 and 2010. Forty-four per cent of 16 to 24-year-old internet users used a mobile phone to access the internet. In 2010, 43% of internet users posted messages to social networking sites.

Research from Experian Hitwise (FT Tech Hub 2011) found that social networks such as Facebook, YouTube and Twitter have superseded entertainment websites as the most popular sites for internet activity. Use of social media now accounts for 12.4 per cent of all time online, with total traffic to such sites increasing by 17 per cent from 2010. According to Shirky (2008):

Electronic networks are enabling novel forms of collective action, enabling the creation of collaborative groups that are larger and more distributed than at any other time in history.

The competitive price of smartphones, cheaper broadband connections and the range of information and services available online have accelerated the acceptance of the world wide web as an essential part of people's lives.

2.2. Social media

The terms [social media](#) and [social networking](#) are often used interchangeably to refer to web-based tools and technologies that support online communication and information sharing. They turn communication into interactive dialogue.

Social media encompasses various tools and services, including:

- blogs
- microblogs (e.g. Twitter)
- wikis
- podcasts
- content sharing services (e.g. flickr, Youtube, Vimeo),
- social networking sites (e.g. Facebook, LinkedIn, Ning)
- social bookmarking (e.g. Delicious)
- location based services (e.g Foursquare)

[Web 2.0](#) is often used as a collective term for the range of technologies and tools that allows users to interact and collaborate with each other using social media.

The more well known services such as Facebook have reported a [substantial increase](#) in the number of registered users and are increasingly used by individuals and organisations to create networks in which they share information, opinion and intelligence).

The growth in the use of social media reflects the changing nature of the world wide web. In the 1990s the web was largely used as a broadcast medium through which users passively consumed information. Now, it offers scope for interactive communication. Jos Creese, then President of the Society of Information Technology Management ([Soctim 2011](#)), noted:

The web is no longer about technology. It is about delivering lower cost services designed around the user. Any public service organisation, therefore, which is not fully integrating the potential of web delivery in financial and customer service strategies, is likely to be under-performing in both areas.

Writing in a Guardian blog, [Barr \(2011\)](#) highlights the possibilities for service users and carers:

Presenting information in a smart, user friendly and attractive manner is becoming an increasingly important dimension in providing any front line service, with websites acting as the public's window to service providers.

- http://en.wikipedia.org/wiki/Social_networking
- http://en.wikipedia.org/wiki/Social_media
- <http://en.wikipedia.org/wiki/Web2.0>
- <http://www.facebook.com/press/info.php?statistics>

2.3. Self directed support

In November 2010, the Scottish Government published [Self-directed support: A National Strategy for Scotland](#) (Scottish Government, 2010). This 10-year strategy seeks to achieve a cultural shift in the delivery of support that views people as equal citizens with rights and responsibilities. Self-Directed Support (SDS) encourages service users to choose, organise and control their social care support in a way that suits them. It is important to note that the values and principles underpinning SDS include the requirement that everyone is provided with unbiased information about the choices available to them. In order to make informed choices about how to spend personal budgets, service users and carers require access to reliable sources of information and advice:

Good information and advice, practical support, appropriate housing options, and joint working between health and social care can assist people in living fulfilled and independent lives, thereby reducing the number of people entering or requiring ongoing support from social and/or health care. (Scottish Government, 2010, section 3).

An additional driver for change was provided by the [Christie Commission](#) report (Scottish Government 2011b) in June 2011:

Unless Scotland embraces a radical, new, collaborative culture throughout our public services, both budgets and provision will buckle under the strain.

Scotland's public services need to be designed with the person receiving them at the centre. The approach must be bottom-up, identifying what individuals and communities actually need and, from there, working out the services that

will best fit those needs. Top-down delivery of uniform, one-size-fits-all services is not efficient, effective - or sustainable. And that means getting individuals and communities involved in the design of those services. (Murtagh, 2011)

2.4. The brief

IRISS commissioned this report in order to find out more about how service users and carers have adopted social media to collaborate, find and share information. The brief comprised the following elements:

- Service users and carers as well as professionals may benefit from a better understanding of the scope and potential offered by a collaborative web 2.0 approach to knowledge sharing in obtaining and purchasing care support services.
- Identify uses of social networks by services users and carers which will capture examples of good practice and evaluate centralised approaches which are effective and sustainable.
- Understand which approaches are effective and sustainable and which are not. In particular, to consider the effectiveness and sustainability of centralised services such as shop4support.com.
- The research should explore various social networking platforms such as Twitter and Facebook to identify relevant communities.
- The report will identify current activity, the potential for development and recommendations on sustainable models.

2.5. Methodology

- Desk research was undertaken to identify relevant studies, key resources and research about social care information online in order to obtain an overview of the relevant issues and to identify emerging themes.
- Over fifty websites providing information about social care services in the public, private and not-for-profit sectors were reviewed.
- Discussions were held with five e-marketplace providers in the care sector to establish the key issues and concerns in delivering online information about social care services.
- Telephone discussions took place with five social care staff in three local authorities contacted through [LinkedIn \(http://www.linkedin.com\)](http://www.linkedin.com), a business-related social networking site, to explore the support they require to act as ‘signposters’ to online services.
- The fifteen responses to the blog post “Do we need an “Amazon style” rating service for care?” were reviewed (Ayres, 2010).
- Online discussions were held with ten service users and carers through Twitter, Facebook and forums to explore how they use social media to access social care information.

3. Care information

Research from the Picker Institute into accessing information about health and social care services (Swain et al, 2007) found that all respondents had, at some point, tried to find out about services available in their local area, such as local general practitioners, dentists and specialist health, social care or voluntary sector services. Most wanted at least basic details in the form of contact names, addresses and telephone numbers, and opening times.

According to the research there was no shortage of information, but the lack of signposting made it hard to find: professionals at the first point of contact did not systematically or proactively provide information about accessing local services; and there was a lack of co-ordination between information providers across boundaries and confusion about responsibility for providing information about the range of services available.

More recent research from the Institute for Public Policy at Oxford Brookes University (2011) and [Melanie Henwood Associates](#) (2011) suggests that the situation has not changed since 2007:

Time and again, people described the struggle to obtain information, advice or advocacy to help them in making life-changing decisions.

It is clear that the internet has changed the way many people find information and communicate with each other. However, if signposting is a problem, what is the solution? In the next sections, public sector activity is examined, followed by an overview of a variety of 'bottom-up' or community-led initiatives that seek to harness the power of the internet.

3.1. Central government

The UK government has made a substantial investment in making information and services available through the internet, the rationale for which was to reduce the need for expensive contact with the public over the phone or face to face.

[Directgov](#) offers information about tax and benefits as well as providing details of consumers' rights with regard to utility companies, landlords or local councils. A review of the 750 government websites suggested that information was being duplicated across many websites, which was both costly and inefficient. In response to a review of the UK Government's online services, which demanded revolution, not evolution, in the way Government services are delivered online, a replacement for DirectGov is now being developed. An experimental prototype, [Alphagov](#), is currently being tested.

[NHS Choices](#) provides health-related advice via Twitter, Facebook and videos. The Twitter feed has over 10,000 followers and Facebook 1300 'fans'. It also hosts communities with discussion forums, including one for [carers](#). Increasingly, NHS Choices is diversifying its offering in terms of both style and content, e.g. a [video in which a doctor talks about how parents and health professionals can work together to support children with disability](#).

- <http://www.direct.gov.uk>
- <http://alpha.gov.uk>
- <http://www.nhs.uk/Pages/HomePage.aspx>
- <http://talk.nhs.uk/forums/51.aspx>

- <http://www.nhs.uk/Livewell/Childrenwithlearningdisability/Pages/Childre...>
- Twitter: [@NHSChoices](#)

In England, NHS Choices offers a facility to search for support and services based on postcode. [Care Information Scotland](#) is a Scottish Government initiative that provides telephone and online information and advice for older people on: how to find services; care at home; care homes; supported housing; paying for care (including explanation of free personal and nursing care and direct payments); how to complain; care standards; and Social Care and Social Work Improvement Scotland ([SCSWIS](#)) inspection reports. It offers a search function which can be filtered by postcode.

- <http://www.careinfoscotland.co.uk/home.aspx>
- <http://www.scswis.com/>

During [National Self Care Week 2010](#) – a Department of Health initiative to encourage people to take more responsibility for their own health by learning about the support and information – a threefold increase on the number of people visiting the self-care web pages on NHS Choices was recorded.

While these figures suggest an increasing demand for online information, there is concern about those without internet access, which the UK government is addressing through the appointment of Martha Lane-Fox, a high profile internet entrepreneur, as the UK's digital inclusion champion and the [Race Online 2012](#) initiative with a mission to create “life enhancing” opportunities for the six million adults in the UK who have never been online.

- http://www.dh.gov.uk/en/Healthcare/Longtermconditions/DH_123950
- <http://raceonline2012.org/>
- Twitter [@Marthalanefox](#)

3.2. Local government

In an effort to provide better signposting to the range of services available, some local authorities have developed, or participated in, ‘place-based’ services in which the user may search for facilities within a specified distance of a specified geographical location such as a postcode.

For example, the Dorset Partnership for Older People Programme (POPP) a collaboration between Dorset County Council, NHS Dorset, Dorset Fire and Rescue, Dorset Police, libraries, community matrons, community pharmacies and others, provides an online search of services and activities for the over 50s: coffee mornings, exercise classes, lunch clubs, meetings and events, as well as statutory services such as libraries and doctors. A number of local authorities are playing a part in the development of online marketplaces.

- <http://www.dorsetforyou.com/popp>

3.3. Popular social media

With some 750 million active users, [Facebook](#) is possibly the best known social network. Facebook's statistics report that 50 per cent of active users log on to Facebook in any given day. The average user is connected to 80 community pages, groups and events, and creates 90 pieces of content each month. More than 30 billion pieces of content (web links, news stories, blog posts,

notes, photo albums, etc.) are shared each month. The increasing influence of mobile technology is reflected in the more than 250 million active users currently accessing Facebook through mobile devices

- <http://www.facebook.com/press/info.php?statistics>
- <http://www.facebook.com>

Twitter is a micro blogging service that allows people and organisations to send and read messages (called ‘tweets’) up to a maximum of 140 characters. The 140 character limit encourages brevity, and tweets frequently contain links to websites for more information. Twitter is estimated to have 190 million users who generate 65 million tweets a day. Despite this volume, it is possible to create networks of people and organisations and follow discussions on particular topics: for example a search for ‘disability’ will find relevant people and organisations.

- <http://twitter.com>

YouTube is a video-sharing website and a powerful medium for communicating information. This [collection of videos](#) on disability illustrates how discussion can create a community around a particular topic.

Many public bodies now use YouTube to disseminate information. For example: [Cambridgeshire County Council's channel](#) carries service users’ and carers’ stories about self directed support and personal budgets:.

Disabled People Against Cuts (DPAC) posted a [video](#) of the Disabled People at the Forefront of Resistance event held in London in February 2011. This provided a wider audience for the event.

- www.youtube.com
- <http://www.youtube.com/user/PosterBrat#g/u>
- <http://www.youtube.com/user/CambsCountyCouncil>
- <http://www.youtube.com/watch?v=uotr-bZ0jC0>

Flickr is primarily for sharing still images (although it does support videos of up to 90 seconds). Users may add their images to groups on particular topics and in this way create communities.

For example, the [Global Friendship Project for Disabilities Rights](#) pools images and fosters discussion on rights for disabled people,

IRISS shares [images on topics related to social care](#) while [The Broken of Britain](#) shared powerful images through Flickr to promote their campaign about the welfare reforms.

- <http://www.flickr.com/>
- <http://www.flickr.com/groups/globalfriendshipproject/>
- <http://www.flickr.com/photos/openlx>
- http://www.flickr.com/photos/eoghan_mac/4418871163/

Location-based social networking tools such as [Foursquare](#) and [Gowalla](#) invite people to share information about where they are (café, restaurant, shop, library etc).

Speaking at a [Local by Social South West event](#) in January 2011, Rich Watts, National Lead for the Strengthening Disabled People's User-Led Organisations (DPULOs) programme and a Director of [Essex Coalition of Disabled People](#) suggested that service users (and citizens more generally) could use this kind of tool to create a repository of all the services, products and resources in a local community, attaching data such as prices, opening times, comments on quality, location.

The job of the local authority in this world then becomes one of catalysing people to share and contribute, and aggregating and sharing this huge wealth of data that has already been created. There is also a role to ensure that there are suitable platforms available for anyone and everyone to be able to access it.

- <https://foursquare.com/>
- <http://gowalla.com/>
- <http://www.scribd.com/doc/47587551/Location-based-social-media-and-social-care>
- <http://www.ecdp.org.uk/>

3.4. Community initiatives

Web technologies have enabled communities to share information, advice and support, thereby increasing neighbourhood social capital, developing new social relationships and networks and engaging socially excluded groups.

Haringey Neighbourhoods Connect

This project aims to improve the quality of life of older people and reduce the cost of care to public service organisations by supporting older people to live independently in their communities with lowered reliance on public services. The project plans to use a blend of social media, online tools and real world interactions to stimulate informal support of older people through active neighbouring.

The project has a particular focus on micro-volunteering, mediated by the community with the support of the local council and Age Concern. The aim is to make it easy for local people to give small slices of time in their neighbourhood when they can, rather than needing to commit to more formal volunteer programmes. Reciprocity is also a key feature of Neighbourhoods Connect. The project is designed to encourage older people to contribute their skills and experience to their community as well as receiving support.

- http://networkedneighbourhoods.com/?page_id=231

Openly Local

Openly local provides details of councils, councillors, public spending and hyperlocal websites (websites focused on a well defined, community scale area). While there is no specific information about social care provision, information is available about the amounts being spent on care and the suppliers of adult services. There are currently 466 [hyperlocal websites](#) listed.

- <http://openlylocal.com>
- http://openlylocal.com/hyperlocal_sites
- Twitter [@OpenlyLocal](#)

Networked Neighbourhoods

The [Online Neighbourhood Networks Study](#) (2010) explored the ways in which people communicate online using local citizen-run websites, the impact of that communication, and the implications for local service providers. The research showed that networked neighbourhoods enhance the sense of belonging, democratic influence, neighbourliness and involvement in their area.

- <http://networkedneighbourhoods.com/>
- Twitter [@NetwkdNeighds](#)

Bowes and Bounds Connected

This project targets two age groups: over 75s who are registered with a local GP but who are not using services and may not be claiming all the benefits to which they are entitled; and over 65s who will be given help and information about their own personal care arrangements.

- <http://www.bowesandbounds.org/>

Your Square Mile

This service is due to launch in late summer 2011. Initially it sets out to match people's interests, skills and experiences with local projects that need support. A second stage will launch as a mutual 'Union for Citizens' offering benefits such as: reduced Public Liability Insurance and Criminal Records Bureau (CRB) checks. Also planned is a local giving platform to donate and receive time, money and resources to and from the local community.

- <http://www.yoursquaremile.co.uk/>
- Twitter [@YourSquareMile](#)

DotComUnity

This is a not-for-profit directory of community services and care information. It allows users to locate what is available in their area and to review and rate their experiences with the listed organisations. It is free for both users and organisations and is funded through advertising and sponsorship. The directory includes support services, employment, legal matters, finance, sports and social activities. A members' area allows events and services to be reviewed and scored using a star-rating system. Over 59,000 events and activities are currently listed across the UK.

- www.dotcommunity.co.uk
- Twitter [@dotcommunity](#)

3.5. Online marketplaces

Online marketplaces (or electronic marketplaces or e-marketplaces) bring together buyers and sellers to communicate, collaborate, and undertake business transactions. The goal is to simplify the buying and selling process, create new market opportunities and open up competition across geographic boundaries.

An online marketplace generates income from transaction fees (usually a percentage of the sale), licensing fees, advertising, the sale of marketing data and through providing additional services such as membership, verification services, and the screening of buyers and sellers. The benefits of online marketplaces include access to a wider range of buyers and suppliers, faster purchase decisions and availability 24 hours a day, 7 days a week. eBay and the already mentioned Amazon are examples of online marketplaces.

Social care online marketplaces typically list products and services in the following categories: accommodation, adapted products and equipment, help, finance, legal and professional services, lifestyle, leisure, culture and community, education and training, health and therapy, nursing care services, personal and domestic support, repairs and maintenance services, carer's services and transport.

Reputation, trust and access are important elements in the purchase of personal care services sold online. In particular, self-funding individuals and their families purchasing care services need an easy way to identify providers who have been 'vetted' by a 'trusted organisation'. It is important that all service providers can demonstrate the quality and value of the services that they offer. It is equally important that service users and commissioners have a method of assessing the quality of services and comparing them when making purchasing choices.

While there are national and international standards applicable to all businesses such as [Investors in People](#), ISO accreditation and [BS EN ISO 9001](#) (British Standards Institution) and regulatory requirements for care providers, there is no recognised scheme for e-marketplace care providers.

In discussions with e-marketplace care providers, concern was expressed about the lack of a recognised quality mark which can acknowledge currently unregulated services as a trusted and approved source. Glasgow City Council, for example, is working with some local authorities in England to develop an online shopping site on the Amazon model, where service users can decide for themselves where they want to spend their personal budgets.

Self Directed Support essentially empowers service users as consumers and one of the challenges we face is making sure they are in a position to make informed choices. Ideally someone would be able to go onto the site and see if others have had a good or bad experience with a particular service or provision. Service users would have the same experience as someone going onto Amazon to check out what other people have to say and what alternative goods or services they checked out or decided to buy.

(On the Record: More for Less with Help from Amazon's Approach, Fitzpatrick, 2011)

[Yorkshire and Humber Joint Improvement Partnership](#) (2010) has explored whether investment in a regional e-marketplace was practically feasible and financially viable for the public purse. A report

commissioned from [Gradus Consulting](#) (not published but shared with the author) suggested that, while there was limited evidence available in terms of costs and savings to councils, the likely price of putting a regional e-marketplace solution in place amounts to less than 1% of the aggregated regional spend on adult social care. The report concludes that a regional e-marketplace benefits from economies of scale in being able to aggregate information and functions.

The consortium of fifteen local authorities in Yorkshire and Humber is now sourcing a provider to deliver an e-marketplace for social care for each participating local authority. It is intended that the e-marketplace provider will supply the specified functionality for each participating local authority to include an electronic information hub for social care customers and an electronic messaging capability between service providers and customers. Customers and service providers will be able to complete financial transactions without the local authority being directly involved. The tender requires that the new system is capable of significant integration with adult social care systems in each participating local authority.

The [Northeast Improvement and Efficiency Partnership](#) has also looked at the the feasibility of setting up an electronic marketplace for health and social care services in Northumberland and Newcastle so that individual budget holders can explore, choose and purchase support, care and equipment online. Part of the project involved considering how the [Shop4Support](#) model might fit the authorities' requirements and how other solutions such as [Slivers of Time](#) might relate to it. Essentially the project explored how this idea could work locally, how it might be modified to support regional working, whether it is worth further investment and has helped to identify efficiency savings that may be offered through the use of an electronic social care marketplace.

The appraisal process appears still to be underway, but full project documentation is available from <http://www.northeastiep.gov.uk/adult/electronicmarketplace.htm>.

A challenge for e-marketplaces is how to achieve a critical mass of contributing suppliers in order to offer variety and choice. For example, [Mobility Scotland](#), a small scale, independent operators offering a spare parts mail order service and emergency call-out facilities for wheelchair repairs in the central belt of Scotland, does not seem to be listed in any of the e-marketplaces that were examined. This serves as reminder that Google's advanced search (choose 'shopping' from the left hand column) is in effect an e-marketplace.

- <http://www.investorsinpeople.co.uk>
- <http://www.bsigroup.co.uk/>
- <http://www.northeastiep.gov.uk/adult/electronicmarketplace.htm>
- [http://www.thinklocalactpersonal.org.uk/library/Resources/Personalisation/YorkshireandHumber/eMarketplace PID November 2010.doc](http://www.thinklocalactpersonal.org.uk/library/Resources/Personalisation/YorkshireandHumber/eMarketplacePIDNovember2010.doc)
- <https://www.shop4support.com/>
- <http://www.slivers.com/>
- <http://www.mobilityscotland.co.uk/>

Examples of online marketplaces

Shop4support

This social enterprise was set up jointly in 2004 by personalisation organisation, In Control, and the e-procurement company, Valueworks. It offers service users, their families and carers a choice of products and services ranging from equipment to aid everyday living to nursing care or legal and financial advice. Users can search by postcode to receive listings and other customers' ratings for all kinds of services, including nursing care and personal and domestic support. They can also manage their finances through 'myaccount' which keeps track of their individual budgets and planned future expenditure.

A community section allows members to share experiences and rate the services and equipment they have bought. A 'mysupport' function is under development. The UK wide site is open to everyone but currently coverage appears to concentrate mostly on England and Wales. Care providers are not charged for being listed on the site but are charged a transaction fee when services are purchased.

- <https://www.shop4support.com>
- Twitter [@incontrolorg](#)

Choose my Care

Choose My Care provides a social care and support services directory aimed at individual budget holders, self-funders, brokers and advocates. Users can search, reserve, book and pay for goods and services from suppliers such as care homes, nursing agencies and home care agencies. The service is free for service users, the care providers being charged a membership fee. The company has extended its services to provide an independent advisory service to visit and report on care homes specified by the client. The service is currently focused on Kent, Surrey, Sussex, Isle of Wight, Dorset and Hampshire.

- <http://www.choosemycare.com/>
- Twitter [@choosemycare](#)
- Facebook <http://www.facebook.com/pages/Choosemycarecom>

Be Care Broker

Be My Care Broker provides search, comparison and purchasing services. Access is free to service users, carers, their families and supporters. Care providers are required to join as members with a free entry level listing. Currently the services listed are predominantly in London and the south east of England but the site reports plans for UK wide expansion. Be My Care Broker is in discussions with local authorities to provide a secure, online virtual payment system.

- <https://www.bemycarebroker.com>
- Twitter [@BeMyCareBroker](#)

Slivers-of-Time

While Slivers-of-Time does not offer a direct e-marketplace, it is a pioneer of an online labour market concept that allows people to sell their labour in small blocks, or "slivers", of time. Greenwich Council, Warwickshire County Council and Hertfordshire Council are pioneering Slivers-of-Time. Service users requiring an assistant for, say, an afternoon, are presented with a list of workers, who have been vetted. Training is available on matters such as food hygiene, confidentiality, moving and handling, medication and lone working. Volunteers are supervised and carers and service users have regular reviews. Slivers-of-Time is being used for the Hertfordshire Council's innovative [Book Your Own Breaks](#) and [Breakaway for Carers](#).

- <http://www.slivers.com/>
- Twitter [@sliversmarkets](#)

Book Your Own Breaks

Book Your Own Breaks is a joint initiative of Crossroads Care, Hertfordshire County Council, social enterprise Slivers of Time and the Department of Health to enable Carers to have more control and flexibility in the types of break they book. The care support workers, who can provide personal care, are vetted, trained, supervised and employed by Crossroads Care..

- <http://www.bookyourownbreaks.com>

Breakaway for Carers

Breakaway for Carers is being piloted by Hertfordshire Council and Hounslow Council. It enables relatives and friends looking after dependent adults to have a break by arranging for someone else to take over for a few hours in the person's home. The service recruits volunteer sitters to offer companionship to older or disabled people. This infrastructure enables local authorities and the voluntary sector to better support service provision, giving them a tool to increase the number of active volunteers.

- <http://www.bookyourownbreaks.com>

The Social Care Card

This membership scheme aims to enable social care workers to demonstrate a basic level of knowledge and work to standards set by a regulated service. The worker will also carry work insurance cover through their membership. An individual or organisation using the system can instantly see where they can get care and support and make a choice about hiring a worker, knowing that the person delivering the care and support has been verified to the highest standard. No further information is available at the moment.

- <http://socialcarecard.com>

AskTara

AskTara was developed by [Community Gateway CIC](#) in partnership with Improvement and Efficiency West Midlands and [Joint Improvement Partnership](#). It offers information and advice

about assistive technology (AT)¹ along with ratings and reviews, user blogs, guides and product demonstrations. An interesting and useful feature is the ability to select and compare products.

- <http://www.asktara.org.uk>
- <http://www.thecommunitygateway.com>
- <http://www.thecommunitygateway.com>
- Twitter [@TCG CIC](#)

Deaf 24/7

The Deaf 24/7 site provides a Directory of British Sign Language and deaf related resources. It offers a bookshop which, interestingly, is powered by Amazon.

- <http://www.deaf247.co.uk/>

3.6. Personal assistants

Some direct payment recipients directly employ a personal assistant (PA) who offers more personalised and flexible support. It is not mandatory for a personal assistant, or website providing a personal assistant matching service, to register with any regulatory body. Discussion with existing e-marketplace providers highlighted the difficulties of verifying basic information beyond the basics of a Disclosure Scotland or, in England, a Criminal Record Bureau (CRB) check and references.

Community Catalysts

Community Catalysts has developed and tested an approach to quality marking that is tailored for micro social care enterprises (Community Catalysts, [2010](#) and [2011](#)). The Quality Mark process has been piloted and Community Catalysts is now collaborating with a number of local authorities to explore how the Quality Mark will fit with existing and emerging procurement and accreditation processes.

- <http://www.communitycatalysts.co.uk/>
- [http://www.thinklocalactpersonal.org.uk/library/Resources/Personalisation/Localmilestones/Addendum to the Practical Guide 4.pdf](http://www.thinklocalactpersonal.org.uk/library/Resources/Personalisation/Localmilestones/Addendum%20to%20the%20Practical%20Guide%204.pdf)
- Twitter [@CommCats](#)

Scottish Personal Assistant Employers Network

Assistive technology or **adaptive technology** (AT) is an umbrella term that includes assistive, adaptive, and rehabilitative devices for people with disabilities and also includes the process used in selecting, locating, and using them. AT promotes greater independence by enabling people to perform tasks that they were formerly unable to accomplish, or had great difficulty accomplishing, by providing enhancements to or changed methods of interacting with the technology needed to accomplish such tasks. Wikipedia.

http://en.wikipedia.org/wiki/Assistive_technology

Unison Scotland has developed a partnership approach with [SPAEN](#) (Scottish Personal Assistant Employers Network) in recognition of the need to provide support for establishing and maintaining good employment practices which benefit both the direct payment holder and the personal assistant.

Local authorities should review their current assessment procedures to ensure that prospective employers are aware of their responsibilities as employers; that funding packages include provision to meet these responsibilities; that reviews include assessments of compliance with employment legislation and that employers are able to either undertake training or access professional advice on employment law. (SPAEN/UNISON, 2009)

Members of SPAEN are people who have taken over the management of their own assistance rather have the state do it for them.

- Web <http://www.spaen.co.uk/>

PA Net Personal Assistants Network

This network provides information and advice about employing a personal assistant and offers a forum to share ideas and best practice.

- <http://panet.org.uk/>

Picking your Pathways

This service aims to inform and signpost people who are looking for training for personal assistants. Many of the training providers on the database have been recommended by people who employ personal assistants.

- <http://www.pickingyourpathways.org.uk>

Being the Boss

Being the Boss was created to address the lack of peer support available to disabled people who employ their own personal assistants. A forum enables information and experience to be shared by disabled people who employ personal assistants.

- <http://www.beingtheboss.co.uk>

An alternative model to the direct employment of a personal assistant by a service user is considered in a research paper commissioned by Unison ([Land and Himmelweit, 2010](#)).

In some European countries the problems involved in becoming an employer are avoided or at least reduced, because the direct payment holder is not the employer. Instead the chosen personal assistant (PA) becomes an employee of the municipal authority They enjoy the same benefits as other municipal employees and can join their pension scheme. In Norway direct payment recipients can now choose a voluntary organisation representing people with disabilities (ALABO) to become their chosen PA's employer... In the Netherlands, from the outset of the scheme in the 1990s, the national Social Insurance

Board became the PA's employer. Direct payment holders can still make this arrangement but with the growth of home-care agencies, direct payment holders have the choice of either paying an agency to provide a personal assistant or arranging for their chosen PA to be employed by an agency.

3.7. Blogs and forums

A blog (from WebLog) is way of creating a simple website without requiring technical knowledge of computer code or web hosting. Individuals and organisations use blogs to share thoughts, ideas and commentaries on news on a particular subject. [BlogPulse](#) estimates the number of blogs at around 152 million. Bloggers write about everything and anything, but writing an interesting blog that people want to read does require skill and dedication.

[Fighting Monsters AMHP](#) (the life and thoughts of a British social worker) is an interesting and challenging blog in which the author writes anonymously about his/her own experience of using social media to support professional development.

- <http://www.blogpulse.com/>
- <http://fightingmonsters.wordpress.com/>
- Twitter [@monstertalk](#)

3.8. Personal social networks

Personal social networks are built around a specific person and a specific situation with the aim of helping that person solve a problem, deal with their situation or come to terms with a change in his/her life. Of course personal social networks exist in the offline world, but these networks can be widened and enhanced by web-based tools. Online personal networks are likely to be much more restrictive in terms of access and membership than say, Facebook.

For example, [Tyze Personal Network](#) is based upon research from the [PLAN Institute](#) which highlighted the power of personal networks to help people face life challenges. The Tyze online personal network is intended to make it easy for people to support someone they care about, and for governments and health care institutions to collaborate with them. It is a secure, online personal network that bridges informal and formal systems of care. Tyze Networks are created around a specific person and a specific situation, and allow connected individuals to share and communicate using messages, events, tasks, stories and photos.

- <http://www.tyze.com/>
- <http://www.planinstitute.ca/>

[Crossroads Care Croydon](#) is using a Tyze Personal Network to extend its services online. People served by Crossroads Care Croydon create an individual online network to enable friends, family, neighbours and carers to connect and collaborate.

- <https://crossroadscarecroydon.tyze.com/>

[My People and Places](#) is a secure, moderated, social-networking website for people with learning disabilities, their carers, families and supporters. My People and Places enable an individual, their family and the professionals around them to work closely together to effectively utilise the

resources available to them. It gives the individual the opportunity to share resources and find a community supported solution.

- <http://www.mypeopleandplaces.com/>

There is considerable research about the value of personal support networks in the context of building social capital within communities. However, it is less clear whether the diverse community support developments available online, ranging from local community websites to personal online support networks, have explored how their individual projects can become more connected and integrated.

4. Rating and assessment

User feedback, recommendations and ratings are an established part of the leading online marketplaces such as Amazon and eBay. A more personalised approach to social care based on giving service users and carers a more direct say over service quality and improvement underpins the regulatory functions performed by the Social Care and Social Work Improvement Scotland ([SCSWIS](#)) and the Care Quality Commission ([CQC](#)) in England.

On 1 April 2011, the work of the Care Commission in Scotland passed to a new, unified body, Social Care and Social Work Improvement Scotland (SCSWIS), which regulates and inspects care services. The formal assessments for regulated care services are available online. SCSWIS provides graded ratings, unlike the Care Quality Commission (CQC) in England who stopped awarding quality ratings in July 2010.

- <http://www.scswis.com>
- <http://www.cqc.org.uk>
- Twitter [@CareQualityComm](#)

Patient Opinion

[Patient Opinion](#) is a pioneer in the rating of health services and the UK's independent feedback platform for health services. It is working to create an ethical and useful system of web-based feedback, which helps improve the standards of care. Patients can post their experiences, suggestions and criticism of their NHS experience.

Patient Opinion has been embraced by the staff at City Health Care Partnership. It is an easy way for service users to say thank you, and importantly to suggest service improvements and of course to voice any concerns. The Feedback we received on Patient Opinion tells us which part of the service is important and valued, which is a great benefit to our organisation.

Andrew Burnell, CE of Hull City Health Care Partnership CIC

A [pilot project](#) has been undertaken to explore how to 'create an ethical and useful system of web-based feedback, which helps improve standards of care'.

- <http://www.patientopinion.org.uk>

- <http://www.patientopinion.org.uk/info/carehomes>
- Twitter [@patientopinion](#)

Care Quality Commission England Adult Social Care Excellence Award

The CQC-backed award, due to launch in April 2012, will be open to all social care providers offering regulated services, including care homes, domiciliary care, supported living and Shared Lives services, rehabilitation and residential substance misuse services.

The scheme is voluntary and there will be an additional cost to achieve the excellence award. Care services will be assessed on a range of criteria including staff training and turnover, daily activities for residents, and the quality of care offered.

The results of the assessments will be published to give families information about what they can expect from individual care services. However this scheme is only open to regulated care providers: micro-providers (organisations with five or fewer staff that are not part of a larger parent organisation) and individual personal assistants are not eligible to apply for the scheme.

- <http://www.cqc.org.uk/yourviews/consultations/excellenceaward.cfm>

Apart from the regulatory care assessments, there are no comprehensive care rating systems available to inform service users and carers about the quality of care provided by individual care providers.

Online marketplaces are developing rating systems but there are insufficient numbers using the services to make the ratings significant. Enabled by Design offers a good example of how service users and carers contribute to reviewing and rating care products.

The model provided by the highly regarded Patient Opinion website would be a welcome addition to enable service users, carers, families and friends to comment about their experiences of care services.

Best-Care-Home

Best-Care-Home is a database of care homes and agencies in England. The site has a focus on personal recommendations from residents, relatives, visitors and staff with users and carers able to comment about care homes which are featured on the website.

Best Care Home Awards are voted for by the users of the website, with specific feedback sought from residents living in the nominated care homes, their family and friends, as well as the view of employees and health care professionals. The award is only open to nursing homes, residential care homes and domiciliary care agencies that have been awarded a 3 star 'Excellent' rating by the Care Quality Commission. The awards are supported by the National Skills Academy.

The fact that not all care homes and agencies are listed does limit the usefulness of the recommendations.

- <http://best-care-home.co.uk>
- Twitter [@voiceofcare](#)

5. Social media in action

This section describes some examples of how individuals and organisations are engaging with social media such as Facebook and Twitter to foster debate, promote their interests and communicate information. It is, however, important to recognise that while social media is not a panacea, it offers powerful and flexible channels for communication.

Princess Royal Trust for Carers

The Princess Royal Trust for Carers has a network of 144 independently-managed Carers' Centres, 89 young carers' services, and interactive websites (www.carers.org and www.youngcarers.net), which deliver 24 hour support to over 424,000 carers and approximately 25,000 young carers.

The Trust has a Facebook group for carers. The Princess Royal Trust for Carers in Scotland claims that a presence on Facebook was a vital factor in getting the concerns of unpaid carers onto the political agenda in the 2011 Scottish Parliament election. A dedicated Facebook page, [Carers Votes Count](#), was set up to update carers and others on policy pledges made by the political parties and to engage carers in local and national campaigning. According to the Trust's Director in Scotland, Florence Burke, campaigning on the internet is ideal for many carers (Naysmith, 2011):

If you are trying to combine a caring role with a job, or with looking after a family of your own, that can make it [demonstrating at Parliament] impossible. But if 3am is the only time when you can be active, you can do that on Facebook.

Carers Votes Count continues to host a vibrant debate, for example, on the likely impact of the [Christie Commission report](#) (Scottish Government 2011)

- <http://www.carers.org/>
- <http://www.youngcarers.net/>
- <http://www.scotland.gov.uk/Publications/2011/06/27154527/0>
- Facebook <http://www.facebook.com/carers>
- Wikipedia http://en.wikipedia.org/wiki/The_Princess_Royal_Trust_for_Carers
- Twitter [@CarersTweets](#)

Enabled by Design

[Enabled by Design](#) is a community of people who are passionate about well-designed, everyday products that challenge the one-size-fits-all approach to assistive equipment. At the first [Social Innovation Camp](#) in 2008, Enabled by Design was awarded first prize as the 'project with most potential'.

Enabled by Design encourages people to share their views and experiences of assistive equipment, share wish lists about improving products and services, and post information, reviews and comments. It is an excellent example of a website that encourages service users with a disability to share information and thoughts about products and services that are improving the quality of people's lives.

- <http://enabledbydesign.org/>

- <http://www.sicamp.org/si-camp-uk/>
- Facebook <http://www.facebook.com/enabledbydesign>
- Twitter [@enabledby](https://twitter.com/enabledby)
- YouTube: <http://www.youtube.com/watch?v=0IOS5IMi9-w>

Action On Hearing Loss (formerly RNID)

Action on Hearing Loss has pioneered the use of video stories as an engaging way of delivering annual reports. The organisation holds ‘social media parties’ online, in places like Twitter, Facebook and YouTube, which have increased user interaction by 416%. The chief executive regularly raises the organisation’s profile by taking part in live Twitter Q&As (question and answer sessions).

- <http://www.actiononhearingloss.org.uk>
- Facebook: <http://www.facebook.com/RNID.Fanpage>
- Twitter [@actiononhearing](https://twitter.com/actiononhearing)
- YouTube: <http://www.youtube.com/user/rnidwebteam>
- Flickr: <http://www.flickr.com/photos/rnid/>

Macmillan Cancer Support

The Macmillan Cancer Support website offers a wide range of resources including forums, social media and support groups, covering practical and emotional issues, coping with loss, treatment and surgery, living beyond cancer and support from friends and family. In 2010, it had 92,729 unique users and a high level of interaction.

Comments from members about their internet support:

‘I’m only strong and positive because I can go online and be as honest as I like about how scared I am. I’ll have people there who can get me through it, and then I can get back to the rest of my life.’

‘I think if it wasn’t for the Internet I’d have probably fallen apart because you feel like you have to turn somewhere and the Internet is the safest place to do it.’

‘There are people out there that need help, and people that are willing to give it. And I think that’s what makes the Internet so great because there are no boundaries. There are no ‘open hours’ if you like. There’s always somebody there.’

- <http://www.macmillan.org.uk>
- Online Community <http://community.macmillan.org.uk/whatsnew/default.aspx>
- Facebook <http://www.facebook.com/macmillancancer>
- Twitter [@macmillancancer](https://twitter.com/macmillancancer)
- YouTube <http://www.youtube.com/macmillancancer>

- Flickr <http://www.flickr.com/people/macmillancancer>

The Broken of Britain

[The Broken of Britain](#) aims to provide a voice for disabled people by campaigning about the impact of the proposed welfare reforms, and the negative coverage of disabled people in the media.

- <http://thebrokenofbritain.blogspot.com/>
- Facebook <http://www.facebook.com/thebrokenofbritain>
- Twitter [@BrokenOfBritain](#)

Martyn Sibley

Martyn Sibley, a service user in a wheelchair, has used his personal experiences to develop “Seminar in your Slippers” a series of 45-minute online sessions providing information to people living with long-term health conditions and disabilities.

- <http://martynsibley.com/>
- Blog <http://enabledbydesign.org/2011/03/update-seminar-in-your-slippers/>
- Twitter [@martynsibley](#)

A Writer in a Wheelchair

A Writer in a Wheelchair is a blog by a wheelchair user and disability advocate who was one of the organisers of the online One Month before Heartbreak campaign which highlighted how the proposed changes to the Disability Living Allowances Allowance reforms could adversely affect disabled people.

- Blog <http://writerinawheelchair.blogspot.com/>
- Twitter [@FunkyFairy22](#)

Can-Do Ability

Can-Do Ability is a blog written by a 25-year old Australian wheelchair user whose objective is to help others with disabilities find answers and solutions to questions that might come up by sharing her personal experiences.

- Blog <http://s.iriss.org.uk/otTIOG>

LiveWorkPlay

LiveWorkPlay is an international example of using social media to grow a community of interest. It sets out to educate the world about what people must do as individuals, organisations, and governments to respect people with intellectual disabilities and their rights in support of a more inclusive community. LiveWorkPlay has more than 2100 Twitter followers, more than 2300 Facebook fans and a popular YouTube channel.

Using social media, the volunteer recruitment campaign tripled the core volunteers from 30 to 90 in less than six months.

- www.liveworkplay.ca
- Facebook: <http://www.facebook.com/peoplefirstottawa>
- Twitter [@MyLiveWorkPlay](https://twitter.com/MyLiveWorkPlay)
- YouTube <http://www.youtube.com/liveworkplayvideo>

Netbuddy

Netbuddy is for swapping practical tips and information on all aspects of supporting people with learning disabilities. The site includes forums and downloadable information packs.

- <http://www.netbuddy.org.uk>
- Twitter [@netbuddytips](https://twitter.com/netbuddytips)
- Facebook <http://www.facebook.com/netbuddytips>

VIKs – Very Important Kids

[VIKs – Very Important Kids](http://www.vik.org.uk) is a three-year lottery funded initiative with Young Minds UK which campaigns to improve mental health services, raises awareness about young people's mental health and well being, and increases young people's involvement in service and delivery.

- <http://www.vik.org.uk>
- Blog <http://www.vik.org.uk/2011/06/28/blog-of-the-month-3>

Young Minds UK

This is a vibrant organisation with an engaging website promoting positive mental health for young people.

- <http://www.youngminds.org.uk/>
- Facebook <http://www.facebook.com/youngmindsuk>
- Twitter [@YoungMindsUK](https://twitter.com/YoungMindsUK)

Carers UK

Carers UK seeks to improve the lives of the UK's six million carers and has an extensive social media presence. In 2010, Carers UK enabled more than 200 carers and professionals around the world to participate in their international conference by broadcasting it over the Internet, saving an estimated £100,000 in travel costs and expenses. It also broadcasts a monthly radio programme

- Web www.carersuk.org
- Facebook: <http://www.facebook.com/carersuk>
- Twitter [@CarersUK](https://twitter.com/CarersUK)

- YouTube: <http://www.youtube.com/CarersUK>
- Vimeo <http://vimeo.com/user3948150>
- Flickr: <http://www.flickr.com/photos/carersuk>

Chill4usCarers

Chill4usCarers actively uses social media to raise awareness and support for carers. The Carers' forum provides information, news and views. Chill4usCarers organises [Computers4carers](#) which provides free computers for carers. It also offers a chat room, open 24 hours a day

- <http://chill4us.com>
- Facebook <http://www.facebook.com/pages/Carers-Chill4us/119697721425673>
- <http://www.computers4carers.co.uk/index.php>
- Twitter [@Chill4usCarers](#)

Brighter Future Workshop

Brighter Future Workshop is charity specialising in the repair, service and sales of new and used mobility equipment including three and four wheel mobility scooters, self-propelled and transit wheelchairs, power chairs, tri-walkers, rollators, lifting aids, tyres, tubes, batteries and other disability equipment. It offers a recycling facility so that equipment that is no longer needed can be re-used.

- <http://www.bfworkshop.co.uk>
- Twitter [@BrighterFuture1](#)
- Ebay http://stores.ebay.co.uk/Brighter-Future-Mobility-Equipment_W0QQ_armrsZ1

Healthtalkonline

Healthtalkonline is the website of the DIPEX charity and enables people to share in more than 2,000 people's experiences of health and illness. It offers videos, interviews and case studies of people's experiences. The information on Healthtalkonline is based on qualitative research into patient experiences.

- <http://www.healthtalkonline.org>
- Forum <http://myhealthtalk.org/>
- Facebook <http://www.facebook.com/pages/Healthtalkonline/203657121184>

Health Unlocked

This initiative aims to gather the knowledge and experience of patients and to share it with a wider audience. Providing information and a sense of support can reduce the isolation and fear of people facing chronic conditions. The difference between HealthUnlocked and other social networks is the level of moderation by the trusted patient groups and charities.

- www.healthunlocked.com
- Facebook <http://www.facebook.com/pages/HealthUnlocked/116339445114685>
- Twitter [@HealthUnlocked](https://twitter.com/HealthUnlocked)
- LinkedIn <http://www.linkedin.com/company/728156>

6. Conclusions

Social media is experiential in nature: it is difficult to fully understand social tools until one has participated and experienced them for oneself. Unlike basic computing skills, such as word processing or spreadsheet manipulation, the core understanding required to make good use of social technologies is cultural, not procedural. Carnegie UK Trust (Charman-Anderson, 2010)

This report illustrates some of the many and innovative ways in which individuals and communities are using social media to find, share and act upon information, knowledge and experience. These 'bottom-up' initiatives to some extent complement the more 'top-down' online marketplaces, such as [Shop4support](#), to create a rich and varied landscape. They also highlight the scope for creativity and innovation, lending support to the notion that social media is *experiential*.

The [Commission on the Future Delivery of Public Services](#), which reported in June 2011 (Scottish Government 2011b), believes that bottom-up initiatives will deliver better outcomes for users. Specifically it recommends (paragraph 8.5):

Managers and leaders within public service organisations should develop and extend the empowerment of front-line staff, to support their engagement with people and communities.

There must be some concern this engagement may be hampered by the continuing inability of much of the public sector to engage with and experience social media and the networks in which these communities are increasingly active.

This inability stems at least in part from policies that routinely block access to Facebook, Twitter, YouTube etc. If professionals working on the front line are unable, or not encouraged, to gain experience of the language and cultural norms of, say, Facebook, they are effectively disempowered from understanding and empathising with their increasingly fluent clients.

[SOCITIM \(2010\)](#) has argued the case for IT managers taking the lead in encouraging their organisations to embrace social media and [IRISS \(2010\)](#) has summarised the arguments for breaking down the cultural and technological barriers that are prevalent in the public sector. The growing importance of social media for service users is a reminder of the importance of having policies and guidelines on using social media at work and ensuring that staff working for public sector organisations develop confidence and competence in its use.

Evidence from the [Social Innovation Camps](#) suggests there is no shortage of [ideas](#) for applying social networking tools, although devising sustainable business models may prove more challenging. Perhaps the market will determine what is sustainable. A challenge for online marketplaces such as [shop4support](#), the [Yorkshire and Humber Joint Improvement Partnership](#), the [Northeast Improvement and Efficiency Partnership electronic marketplace](#) or the [Glasgow City Council initiative](#) will be to achieve the critical mass of customers and service providers necessary to be economically viable and sustainable.

In this respect, it is worth noting that the established players such [Amazon](#) and [eBay](#) (see Brigher Future Workshop above) already offer goods, if not services, relevant to those receiving support. A number of care providers have already established Facebook groups, and in the future, may choose to use Facebook and the established e-marketplaces such as eBay and Amazon to market their care services.

The marketplace for social care products and services is likely to continue to evolve as the online marketplaces mature, as the mainstream providers extend what they offer and as more service users take up the opportunities for networking afforded by social media. Because of its inherent decentralised, or bottom-up, nature, social media may offer the key to sustainability. With that in mind this report is available [online \(http://comment.iriss.org.uk/content/digital-engagement\)](http://comment.iriss.org.uk/content/digital-engagement) where you are encouraged to comment, discuss and share online social care resources which you have found helpful.

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