THE INTERNET AND GOVERNMENT DISABILITY POLICY DEVELOPMENT

IN THE UNITED KINGDOM

Des Power

School of Education and Professional Studies

Griffith University

Gold Coast, Queensland

and

Mary R. Power

Faculty of Humanities and Social Sciences

Bond University

Queensland

Correspondence:

Des Power

d.power@griffith.edu.au

Abstract

People with disabilities represent a significant but often overlooked proportion of the British population (10 million people, 18%). They are publicly represented by organisations consisting of and managed by people with disabilities themselves (e.g., British Deaf Association) and organisations for their benefit, often managed or advised by people from the "helping professions" (e.g., Royal National Institute for the Deaf). Many community organisations attempt to influence government policy by both direct lobbying with government and its agencies. They use the media to gain awareness and support . This paper investigates how a sample of key disability organisations use the Internet to inform their members, publicise their activities, describe the need for policy changes or new initiatives and encourage political action to redress what they see as inequalities.

This paper examines the policy campaigning of major organisations representative of a range of types of disabilities as found on their websites and asks whether these campaigns influence government policy by examining a number of both central and local government initiatives to see the extent to which they reflect the campaigns of the organisations. The paper finds that disability organizations use websites to put their messages about disability issues and to put the views and standpoints of disabled people in the public domain and that in an election year they give clear instructions to disabled people on how to increase the power of their vote by actively participating in activities through which <u>political parties</u> will understand their views.

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People with disabilities

People with disabilities represent an often unrecognized but significant proportion of the population of the United Kingdom. Figures available on the *Employers' Forum on Disability 2010* site (Disability in the UK: <u>http://www.efd.org.uk/media-centre/facts-and-figures/disability-in-uk</u>) show that about ten million people (18% of the population) meet the *Disability Discrimination Act* (DDA; 2005) definition of disability. Nineteen percent of them are of working age, but only 50% of these are employed, with the rate of unemployment rising from 9% in the early adult group to 33% in the 50 to retirement age group. Of the 2.4 million people with disabilities receiving benefit allowances nearly one million would like to work. Despite the level of unemployment, it is estimated that the annual purchasing power of people with disabilities is £80 billion.

Definition of disability

The DDA defines a disabled person "as someone who has a physical or mental impairment that has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities". Disabled people include those with mental and physical disabilities, learning difficulties, vision and hearing impairments whose "affected capacities" can include "mobility, manual dexterity, speech, hearing, seeing and memory" (Directgov: Disabled People).

Definitions of disability are important in that they influence the way in which people with disabilities are viewed in the public mind and how they are treated in the community as regards their education, employment, family and social life. As the Northern Officer Group (n. d.) of people with disabilities who work in local government has said,

a definition can place limits not merely on what is possible, but what is 'thinkable' ...

(p. 2). [Disability is a result of] social organization (for example, work practices, buildings or products) that takes little or no account of people who have impairments, and/or social organization that creates segregated and second-rate provision (for example, segregated welfare provision, transport, employment, education and leisure facilities).

Society is shown to disable people who have impairments because the way it has been set up prevents us from taking part in everyday life. Disability is located in the way society is organized; it is the restriction of activity caused by inadequate social organization (p. 5).

Communication technology and disability policy

Margetts (2010) has stressed the importance of technological developments and their impact on policy development, perhaps especially in the case of marginalized groups such as people with disabilities. "Basically, technological developments tend to make easier policies geared at some particular group or category of people. … Treasure [government funding] … can be targeted conditionally towards groups according to their particular circumstances (p. 10)". The present research examines how disability organisations use the Internet to attempt to influence policy and the extent to which such attempts are successful and draw "Treasure … [towards] their particular circumstances".

Government activities

A succession of British governments has enacted a series of measures concerning disability, culminating in the *Disability Discrimination Act* (DDA) and its Amendment in 2005, both superseded by the *Equality Act* of 2010. The *Equality Act* continues a number of established Government initiatives, including such agencies as the *Office for Disability Issues*. Other Government organisations related to disability continue in existence, including the *Equality and Human Rights Commission* and the *Office for Disability*

Issues. The latter includes an advisory group of people with disabilities: *Equality 2025 - the UK Advisory Network on Disability Equality*. The Office for Disability Issues has a "Roadmap" aimed "to bring about equality for disabled people by 2025". It has a range of programmes to assist with this aim, including "Producing Better Information for Disabled People: A Toolkit for Local Government" (Office for Disability Issues, n. d.). As early as 2005, the Prime Minister's Strategy Unit had produced a Report, "Improving the Life Chances of Disabled People".

A major part of the remit of the *Equality and Human Rights Commission* concerns disability issues (<u>http://www.equalityhumanrights.com/our-job/what-we-do/our-</u> <u>business-plan/disability-equality/</u>) and it has a *Disability Committee*

considered necessary by the Government because of the highly distinctive nature of disability equality law, in particular the duties to make reasonable adjustments, and the complex technical and ethical issues associated with promoting disability equality. The Disability Committee has decision making powers in relation to those matters which solely concern disability, and the Commission must seek the advice of the Committee on all matters which relate to disability in a significant way

(http://www.equalityhumanrights.com/our-job/who-we-are/disability-committee/).

In April 2010 the Government enacted the *Equality Act* which consolidated and streamlined nine previous anti-discrimination acts and about 100 "statutory instruments" (<u>http://www.equalityhumanrights.com/legislative-framework/equality-bill/</u>). The Act is due to come into force in October 2010. The new Government has indicated that it will implement the Act.

In addition to UK Government efforts the United Nations has established a *Convention* on the Rights of Persons with Disabilities (2006), including an Optional Protocol, to both of which the UK Government is a signatory. There are eight guiding principles that underlie the Convention:

1. Respect for inherent dignity, individual autonomy, including the freedom to make one's own choices, and independence of persons

2. Non-discrimination

3. Full and effective participation and inclusion in society

4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity

5. Equality of opportunity

6. Accessibility

7. Equality between men and women

8. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

The Protocol gives individuals or groups the power to bring to the Convention Committee complaints about matters in which they believe their country has breached the rights guaranteed to them by the terms of the Convention. Complaints may be activated "only after domestic remedies have been exhausted", and is not retrospective.

Disability in the Community

In the past forty years beliefs about and attitudes towards people with disabilities have changed considerably. It is now widely accepted that although a disabling condition (an impairment) may "reside within" the individual, the condition need not become a handicap in everyday life if the social environments in which individuals live accommodate their needs (Barnes, 2007; Oliver, 1996).

Barnes states that disability activism should be seen in the same light as campaigns for equal rights by other marginalised groups.

The main problems faced by people viewed as disabled, or 'with disabilities', stems

from disabling environmental, economic and cultural barriers. Disability is therefore an equal rights issue on a par with other forms of unjustifiable discrimination and prejudice such as racism, sexism, heterosexism and homophobia (p. 204).

This stance fits well with "Standpoint Theory" (Harding, 2003) which holds that people inevitably have a point of view from which they interpret the world—notably the social world and the place of individuals and groups within it (especially marginalized groups such as disabled people). Standpoint theory is critical of the existing social order and argues that those who have experienced life as part of a disadvantaged group have a wider view of reality than those more power in society and that that marginalized groups can see new possibilities through "envisioning more just social practices" (Hartsock, 1997, p. 373). All standpoints are partial, but those from lower in the hierarchy see more. Standpoints are "achieved through experiences of oppression added to active engagement, reflection, and recognition of the political implications of these experiences" (West & Turner, 2010, p. 508). O'Brien Hallstein (2000) sees standpoints as political stances "not achieved by individuals acting alone. Instead, they are achieved through collective interaction and dialogue with others" (\P 17). This description of a standpoint can be applied to disability organisations that create websites for discussion of issues of central interest for contributors and viewers. The Internet has the advantage of giving a voice to marginalized groups. It is the dissemination of the standpoint of representative disability organisations that is examined in this paper.

Disability Organisations

A number of large national organisations promote the interests and welfare of people with disabilities. Many of these maintain websites to communicate with their constituents, with the wider public, and with those in government.

Among the largest are RADAR (Royal Association for Disability and Rehabilitation; http://www.radar.org.uk/radarwebsite/; for some years RADAR has provided the Secretariat

to the "All Party Parliamentary Group on Disability" of members of both Houses interested in these issues), the Disability Alliance; <u>http://www.disabilityalliance.org/</u>), the Royal National Institute for the Deaf; <u>http://www.rnid.org.uk/</u>), the Royal National Institute for the Blind; <u>http://www.rnib.org.uk/Pages/Home.aspx</u>), "Sense" (representing deaf-blind people; <u>http://www.sense.org.uk/).</u> DIALUK provides a national network of 140 disability information and advice services. It is funded by a range of trusts and businesses. Most of its workers are volunteers and many are disabled themselves (<u>http://www.dialuk.info/</u>).

"Scope" is concerned with people with disabilities generally, but has a special interest in working with and for people with cerebral palsy (<u>http://www.scope.org.uk/home</u>). The Learning Disability Coalition is the major organisation in that field. It has as members 15 major organisations in the LD field

(http://www.learningdisabilitycoalition.org.uk/aboutus.asp) and an Advisory Committee with media, academic and health professional members as well as MPs and Members of the House of Lords. Leonard Cheshire Disability has a general concern for disabled people (http://www.lcdisability.org/).

"People First" provides training and consultancy on learning disability matters for groups and individuals, mounts conferences on learning disability issues and publishes a wide range of materials in the field (http://www.peoplefirstltd.com/what-we-do.php). People First

is an organisation run by and for people with learning difficulties to raise awareness of and campaign for the rights of people with learning difficulties and to support self advocacy groups across the country. People First promotes the social model of disability. This is a way of thinking about disability that says it is society that needs to change to include disabled people. We should not have to change to fit in with society. We are against the medical model of disability, which is the view that being disabled means there is 'something wrong' with you. Clearly disability organisations are concerned with changing public attitudes towards disability and widening acceptance of the disability standpoints within the community. In addition they are "political" in the sense that they want to influence government policy towards disabled people.

This paper investigates how disabled people and their carers and representative organisations present views of disability on the internet, and how organisations for the disabled have used their websites to attempt to influence government policy and the political process. In the period of the 2010 election campaign many did this by encouraging their members to participate in the political process by voting and by contacting political candidates as well as publicising their views on matters that <u>affect</u> them to the politicians and the public at large.

METHOD

This project examined the Internet for sites of British organisations which promote the interests and welfare of people with disabilities and the response of government and its agencies to these representations. The Internet generally was examined on such terms as "disability UK", "people with disabilities UK" to generate a list of 37 such organisations. The websites of the 37 disability organisations and government agencies were examined or contact was made to the email address listed in the case of organizations whose websites we were unable to locate. We identified the major policies or statements of aims on each of the websites and listed their activities related to or covering the 2010 Election to ascertain their lobbying and publicity efforts. This provide<u>d</u> insight into the special campaigns of the disability organisations and the response of politicians and government agencies to them as regards legislation and regulations.

RESULTS

Organisation:	Major	2010 Election
Web or Email Address	Policies/Statements	Coverage
Association for Real Change: www.arcuk.org.uk	Policy Development and Promoting_Best Practice: National & Local Staff Learning & Development Training CRB Disclosure Service Information and Support	Joint Activities With Learning Disability Coalition to Influence Government_Policies
BILD (British Institute for Learning Disabilities): www.bild.org.uk	Hate Crime Inquiry Positive Behaviour Support: Defining Good Practice BILD Guides on LD Issues Hearing From The Seldom Heard Better Lives, Better Communities Quality Network & Consulting.	Information On Parliamentary Activities
British Computer Society Disability Group: graham.mclaughlin@hq.bcs.org.uk	No website found; no response to correspondence	
British Deaf Association: england@bda.org.uk	Human Fertilisation & Embryology Act Protest	
Connect:(Communication Disability) info@ukconnect.org	Information: Publications & DVD on Aphasia Services for People With Aphasia Conversation Partner Scheme Training Healthcare Workers	Contact with Local MPs and Candidates re National Stroke Strategy
Connect2you: Rachel@connect2you.org.uk	No website found; no response to correspondence	
DIALUK: www.dialuk.org.uk	Disability Information & Advice Welfare Rights Advice Training	
Disability Alliance: office@disabilityalliance.org	Party Policy Analysis Policy Manifesto	Party Policy Analysis Campaigns Page
Disability Law Service: advice@dls.org.uk	Advice & Information on: Discrimination Consumer Affairs Community Care Further & Higher Education Employment Welfare Benefits	

Website analysis of disability organisations' policy

Downs Syndrome Association:	Publications & DVDs	Policy Campaign:
www.downs-syndrome.org.uk	Information on Aspects of Life	Employment &
	With Downs Syndrome	Human Rights
Foundation for People With	Consultancy & Training	Campaign to
Learning Disabilities:	Raise Awareness of Issues	Influence Policy on LD
www.learningdisabilities.org.uk	Conduct Research and Projects	
	Information Publications	
Learning Disability Coalition:	Unified Voice to Government via	Ask MP to Protect
a.cox@learningdisabilitycoalition.org.uk	Submissions & Consulting	Frontline Services
	Assess Resource Requirements	Social Care Discussion
	Monitoring Social Care Provision	Needed in Election Debate
Leonard Cheshire Disability:	End disability poverty	Lobbying Candidates re
info@LCDisability.org	& discrimination	Neighbourhood access &
	Establish campaign action groups	equity for disabled people
	Meet Government agencies re	
	disability issues	
Mencap:	Offer <u>s</u> Service Advice	Lobby To Promote
www.mencap.org.uk	Runs Residential & Day Care	Change To
	Services	Laws & Services
National Autistic Society:	Recognition of Needs	Campaigner Training
www.NAS.org.uk	Education & Employment	Campaign "Toolkit"
	Campaigner Training	Email Campaign
	Campaign "Toolkit"	(7500 sent)
	All-Party Parliamentary	
	Group on Autism	
National Blind Children's Society:	Family Support & Information	"Every Disabled Child
enquiries@nbcs.org.uk	Educational Advocacy	Matters" Campaign
	CustomEyes Books	
	Equipment Provision	
	Recreational Activities	
National Valuing Families Forum &	Support Local Disability Program	
National Family Carer Network:	Advice To Local Authorities	
www.familycarers.org.uk	Advice to Government	
	Standing Commission On Carers	
	National Learning Disability	
	Programme Board	
People First: (Learning Difficulties)	Statement On Hate Crime	
www.peoplefirstltd.com	Self-Advocacy Training	
	Easy Read Service	
	Accessible Format Publications	
PMLD Network: (Profound &	A Right To Be Included, Heard,	Inform Government and
Multiple Disabilities)	Considered, Understood,	Politicians About
pmldnetwork@mencap.org.uk	Obtain Appropriate Healthcare	PMLD Needs
Queen Elizabeth Foundation For	Increase Independence	
Disabled People:	Improve Life Skills	
www.qefd.org	Provides	
	Normal Opportunities,	
	Residential Care	
	Independent Living Services	
	Mobility Services	
	Neurorehabilitation Services	
	Vocational Services	

RADAR (Royal Association for	Accessible Taxis	Negotiating with Government:
Disability and Rehabilitation):	Welfare Reform	re Welfare Reform Bill
Marije.daidson@radar.org.uk	Contra Assisted Dying	re Access to Work Scheme
· · ·		re Independent Living Bill
Real Life Options:	Human Value & Worth	Joint Activities to Influence
www.reallifeoptions.org	for LD People	Government Policies
	LD People Right to Community Participation	
Royal Association for Deaf People:	Development in: Legal,	
info@royaldeaf.org.uk	Advocacy, Employment, BME,	
	Training Activities.	
Royal National College for the Blind:	Nothing on website; no response	
info@rncb.ac.uk	to correspondence	
Royal National Institute for the Blind:	Seek radical change in policy and	Voting & Elections:
www.rnib.org.uk	provision to deliver independence	Information Page
	inclusion and an end to the scanda	for Blind & Low Vision
	unnecessary sight loss.	People Policy Points Campaign
Royal National Institute for the Deaf:	Importance of Sign Language	Media Campaign: Put
informationline@rnid.org.uk	Educating Deaf People on Politics	
intornationine e mid.org.uk		"Deaf Awareness":
		Information for Candidates
SeeAbility:	No website found; no response to	
enquiries@seeability.org	correspondence	
Sense: (deafblindness)	Make Deaf/Blindness	Sample Letter to Candidates
info@sense.org.uk	an Election Issue	Accessibility Workshops
Caracter (Caracter at Datasa)	A approxibility	for Candidates
Scope: (Cerebral Palsy)	Accessibility: Public Awareness Campaign	Members' Electoral Rights Factsheet
response@scope.org.uk	r ublic Awareness Campaign	Campaign Letter Template
Turning Point: (Learning Disabilities)	"New Vision" Needed on Social	campaign Detter Template
www.turningpoint.co.uk	& Health Care	
United Kingdom Women's Forum	No website found; no response to	
for Disability Affairs:	correspondence	
llamedos@enna.fsnet.co.uk		
United Response: (Learning Disabilities)	No website found; no response to	"Every Vote Counts" Project:
www.unitedresponse.org.uk	correspondence	Election Materials
		for LD People

Table 1: Details of activities and policies of disability organisations contacted

Analysis of Table 1

Major policies and statements could be categorized into actions that served four broad

categories:

1. Access to the broader community: To highlight disabled people's different needs for

<u>improved</u> training, accessibility, <u>and</u> communication that would enable them to

participate more fully in their social and working worlds and which draw attention to "the restriction of activity caused by inadequate social organization" (op cit_above, p. 2).

- 2. Description of existing services: To describe (and encourage the use of) services which meet needs by providing support, advice and information.
- 3. Rights and social justice issues. In terms of standpoint theory, "envisioning more just social practices", and stating that people with disabilities have rights to be included, heard, considered, understood and to obtain appropriate health care.
- Direct political action: mainly in opposing Acts such as the Human Fertilisation and Embryology Act and in two cases drawing attention to and supporting the Hate Crime Inquiry.

Summary of Table in terms of the above classifications

- Access to the broader community: This included such provisions as access to transport and buildings/public spaces as well as "access" in the sense of disabled people being better understood and accepted by non-disabled people.
- Description of existing services: Organisations used their websites to publicise their services to their members and to attempt to make the general public aware of these services and in many cases to invite people to join in assisting with those services in their localities; e.g., the "Neighbourhood Access" campaign of Leonard Cheshire Disability.
- 3. Rights and social justice issues: Organisations stressed the rights of disabled people as citizens and fellow humans and pointed out where better treatment was required in these areas; e.g., the "Right To Be Included, Heard, Considered, Understood, and Obtain Appropriate Healthcare" campaign of the PMLD Network.
- 3. Direct political action: Most disability organisations seized the opportunity to

take political action through providing advice to members on how to vote, how to campaign, how to lobby, and how to inform government and politicians about particular needs. Some provided templates for campaign letters and emails and campaigns were designed around the particular needs of groups such as learning disabled, autistic, blind, and deaf people and people seeking accessibility to their local environments.

Disability organisations influencing politics and policy development

The British General Election, 2010

A British General Election was held in May 2010. Most disability organisations took this opportunity to urge their members to be active in lobbying their local candidates about disability issues and to issue media releases about policies they would like to see adopted by whichever of the parties came to power. Many of these activities were mediated by the Internet; by both the organisations' own website announcements and by special postings direct to the Internet.

Political parties' election manifestos awareness of disability

The major competing Parties' election manifestos were examined to see if the concerns expressed in the websites analysed above were reflected in them. There were similarities in several matters promised by the Parties. Both the Conservatives and Labour said they would protect the Child Trust Fund and Labour said it would add £100 extra to it for all disabled children. The Conservatives said they would introduce an "incapacity benefit" to help disabled people live independently and give them "opportunities to be more equal". Labour promised to introduce a new aspect of the National Care programme to enable disabled people "to lead dignified and independent lives, free of discrimination and with the support to which they are entitled".

All three <u>major</u> Parties made promises in the area of providing better employment

opportunities for disabled people. Labour said it would seek to help people move from the Incapacity Benefit or the Employment Support Allowance to paid employment. The Liberal Democrats would give disabled job seekers "better practical help to get work" and reform the Access to Work provisions "so disabled people can apply for jobs with funding already in place for equipment and adaptation that they need" and "tackle" work discrimination on the grounds of disability. The Conservatives said that they would make changes to some benefits, and "will reassess all current claimants of Incapacity Benefit. Those found fit for work will be transferred onto Jobseeker's Allowance [but] recipients of Incapacity Benefit who are genuinely disabled will continue to receive the financial support to which they are entitled". No definition of "genuinely disabled" was supplied.

Organisations' policies on the Internet

It is difficult to trace <u>specific</u> policy or service practice outcomes <u>directly</u> to the Internet activities of disability organizations, but as shown above, their sites were active in promoting ways in which government, its agencies and individual politicians could assist in achieving their aims for their members. We examine below individual organizations under type of disability headings.

Deafness

The Royal National Institute for the Deaf posted to the Internet and directly to a wide range of media outlets its "Put hearing loss at the top of the election candidates' agendas" <u>message</u>. In that post they urged members to encourage candidates to be accessible to people with hearing loss by using venues with induction loops for hearing aids, amplifying speeches sufficiently, having personal conversations in well-lit places where they can be lipread, and telling candidates about good practices in accessing speech in everyday life and urging them to promise to do what they can to "improve the everyday lives of constituents who are deaf or hard of hearing".

In the same field the BSL:UPTAKE unit at Heriot-Watt University, set up in 2009 "with a remit to improve dialogue and knowledge exchange between the world of politics, public policy and the Deaf community", has been particularly active in Scotland as well as the UK generally in promoting the needs of sign language-using Deaf people and making materials available in BSL (<u>http://www.bsluptake.org.uk/?p=1519</u>). BBC News published an item on April 25 by Tessa Padden of BSL:UPTAKE, "Deaf Voters 'Unheard' by Politicians" explaining that Deaf people feel excluded from the political process

(http://news.bbc.co.uk/2/hi/uk_news/politics/election_2010/scotland/8640584.stm).

UPTAKE's Blog 5 in BSL and written English is devoted to "Deaf People – Voters and Citizens – UK General Election 2010", and it has a "Government and Politics" section aimed at educating Deaf people about politics and the political process

(http://www.bsluptake.org.uk/info/?cat=6).

Blindness

The Royal National Institute for the Blind website had a "Voting and Elections" page on its site (http://www.rnib.org.uk/livingwithsightloss/yourrights/Pages/voting.aspx) which told blind people how register, what to do at a polling station, how to proxy or postal vote, how to "make a difference"—contact their local candidates and ask them about their support for blind and partially sighted people (specifying five policy points to stress), and provided audio and print clips about improvements for blind people that took place in the previous Parliament and the possible effect on RNIB's work with whichever Party won the election. A "Your Rights" page of the site detailed the implications of the Disability Discrimination Act and the Human Rights Act as far as blind and partially sighted people are concerned. These comments on the Acts are directed more to members than to policy or politicians generally.

DeafBlindness

The major organisation which represents deafblind people is "Sense". Sense organized

a major campaign for the needs and rights of deafblind people during the Election, "Make Deafblindness an Election Issue". It provided its members with a sample draft letter to send to their local MP <u>and candidates</u> and organised "How to Run an Accessible Campaign" workshops for candidates.

Physical disabilities

Several organisations represent the needs of physically disabled people. <u>A</u> major organisation, focusing particularly on people with cerebral palsy, is "Scope" (http://www.scope.org.uk/campaigns). Scope combined with the "Polls Apart: Opening Elections to Disabled People" campaign (http://www.pollsapart.org.uk/) to raise public awareness of the needs and rights of physically disabled people with their own members and with candidates about accessibility of polling stations and provided members with a Factsheet about their electoral rights. They also provided to members a template letter to local authorities and a template media release.

Learning disabilities

The major alliance of groups representing the interests of people with learning disabilities is the Learning Disabilities Coalition. Descriptions of the election activities of its 15 members can be found at http://www.learningdisabilitycoalition.org.uk/Write_to_MP.asp. The major emphasis was on persuading candidates to run campaigns accessible to people with disabilities and stressing the importance of members making candidates aware of the issues which impede the progress of such people. They also mounted websites and <u>ran</u> events which <u>taught</u> their members who have disabilities about the electoral process and how to cast a vote.

Leonard Cheshire Disability ran a training event at each of the political Party conferences which attracted senior representatives from each of the Parties <u>with the aim of influencing</u> their election Manifestos and Party platforms (http://www.lcdisability.org/?lid=11450). It encouraged members to become involved in the

political process with the "My Vote My Say" campaign. The society also has a "campaigns stall" staffed by volunteers which circulates to many local public events. In Scotland it established the "Citizenship Academy" which "aims to empower disabled people across Scotland to become more actively involved in their local communities, with an emphasis on learning about Scotland's decision making processes and how they can be part of them" (http://www.lcdisability.org/?lid=7492).

Disability generally

Two major organisations represent the interests of people with disabilities more generally than the disability-specific ones <u>examined</u> above. These are the Disability Alliance (DA) and DIALUK.

DA <u>was</u> especially active in the context of the election (<u>http://www.disabilityalliance.org/</u>). It provided an analysis of the major parties' manifestos re disability matters (<u>http://www.disabilityalliance.org/election.htm</u>) and conducted a "National Disabled People's Poll ... to increase awareness of disabled people's priorities and concerns". The Poll was conducted by ComSec in May 2010 and found generally supportive public attitudes towards the needs and aspirations of disabled people

(http://www.comres.co.uk/page165193724.aspx). Seventy percent of people surveyed agreed that "The Government does not do enough to support disabled people" and 90% that "Other people do not really understand the negative attitudes faced by disabled people".

DA provide<u>d</u> a "Campaigns Page" (<u>http://www.disabilityalliance.org/campaign.htm</u>) which mention<u>ed</u> such matters as improving the takeup of welfare benefits and tax credits, a Manifesto on recommendations for routes out of poverty for disabled people and their families and, <u>in alliances with</u> several other <u>groups</u>, <u>methods of</u> dealing with ways out of poverty, making all medical prescriptions free for people with long-term conditions and disabilities, improving streetscape and other public spaces to meet the needs of all disabled

people, provision of fuel payments in winter for those eligible, and a number of other issues.

Special interests

As well as these general issues taken up in the context of the General Election, organisations have continued to use the Internet to publicize specific issues from their particular interests.

The British Deaf Association, like many disability organisations, was very concerned about the implications of the Human Fertilisation and Embryology Act Clause 14, Section 4, Number 9 which inter alia stated that

Persons or embryos that are known to have a gene, chromosome or mitochondrion abnormality involving a significant risk that a person with the abnormality will have or develop—

(a) a serious physical or mental disability, ... must not be preferred to those that are not known to have such an abnormality.

This came to prominence in the Deaf community when Baroness Deech stated in the House of Lords in November 2007, "I hope that your Lordships will be pleased that the deliberate choice of an embryo that is, for example, likely to be deaf will be prevented by Clause 14". Several Deaf organisations, including the BDA, said this was essentially eugenic in its effect on Deaf people and wrote to the House of Lords to protest (see also Emery, Middleton & Turner, 2010). However, the Act was passed with that clause unchanged in November 2008.

The RNIB has launched a "UK Vision Strategy" with an "Action Pack" for local use, instituted the "Lost and Found" campaign directed at local Primary Care Trusts "to ensure that information, advice and support is available to everyone losing their sight" and provided to members a Guide and a template letter for that purpose.

Leonard Cheshire Disability <u>ran</u> an "Action for Access Design Competition" which <u>sought</u> images to support their "Action for Access" (<u>www.accessforaction.org</u>) campaign which provides volunteers with materials to survey their local neighbourhoods and make the results widely known, including to local and national politicians.

RADAR campaigned against any introduction of "assisted dying" or "physicianassisted dying" and so far the House of Lords Bill on this topic has not been successful. RADAR also campaigned for welfare reform to assist disabled people, for the provision of more accessible taxis, and "a fundamental review" of provisions for disabled people in the Access to Work Scheme, briefed relevant people on the implication of the 2010 Equality Act, and supported some provisions of the Personal Care at Home Bill.

United Response, mainly concerned with learning disabled people₁ developed <u>the</u> "Every Vote Counts" project (funded by The Electoral Commission) which provide<u>d</u> a pack of materials on the electoral process specially designed for LD people

(http://www.everyvotecounts.org.uk/pack/index.php). They provided other special educational materials, including "Making Money Easier", information about bullying of LD school children, and produced "Moving on and Planning Ahead: A new easy to use guide to assist people with learning disabilities who want to live more independently to plan for the future".

Among the most active groups is the National Autistic Society (http://www.autism.org.uk/) which, among other matters, campaigned for more public recognition of the needs of autistic people and better educational and employment opportunities for them. It trained local campaigners, and it developed a "Campaign Toolkit" for groups to work on local issues. It is active in monitoring matters to do with autistic people that come before the courts—the best-known being that of opposing computer hacker Gary McKinnon's extradition to the United States. It also supports and informs an All-Party

Parliamentary Group on Autism. The Society reported that its members sent 7500 emails to candidates during the election Campaign.

Turning Point, another organisation working for and with LD people, put forward the hope that the new Government will take up the "new opportunity for a new vision and a renewed energy in tackling the needs of millions of people who need good and integrated health and social care", commented on the shortcomings of the May Parliamentary health care debate as regards the needs of people with disabilities and mental health problems, and welcomed most aspects of the Social Care White Paper.

The Downs Syndrome Association campaigned on behalf of people with Down's Syndrome on human rights, employment, and access to education and has also provided a "Tell It Right, Start It Right Action Pack" for the use of its members.

Survey

In order to triangulate our observations of websites with the insights and aim of those who designed them we formulated a questionnaire for disability organisations asking about various aspects of their use of the Internet to further their aims (Appendix). A list of 37 major organisations were sent the questionnaire (Table 1) first by email to the address listed on the site and then by mail to the CEO of the organisation. From the 37 organisations so surveyed we received only three replies and so are not able to triangulate the findings of the observations and monitoring of websites.

DISCUSSION

Some commentators (e.g., Barnes & Oliver, 1995, p. 115) have pointed out that there are some dangers for disability advocates in both "getting too close to the Government ... [and in] moving too far away".

To get too close to the Government is to risk incorporation and end up carrying out their proposals rather than ours. To move too far away is to risk marginalisation

and eventual demise. To collaborate too eagerly with the organizations for disabled people risks having our agendas taken over by them, and having them presented both to us and to politicians as theirs. To remain aloof risks appearing unrealistic and/or unreasonable, and denies possible access to much needed resources.

While these comments serve as a warning, the Internet has become a significant tool for disability organizations to connect with and inform their own members about their services and policies as well as to provide an "ever-on" source of information for <u>the</u> media and the public at large about the aspirations and needs of people with disabilities. Thus the Internet allows minority standpoints to be made available to a much wider public and increases the control of disabled people over the image that they wish to present of themselves.

In policy and life management and improvement terms, however, it is clear that the Internet has also brought the potential for new inequities, particularly for those who lack Internet skills or access, among whom people with disabilities are often included.

Digital exclusion has been shown to be associated with social and economic exclusion (Helsper, 2008, 2009) and such inequities between the digitally included and excluded could be exacerbated as electronic interaction becomes the norm, with the potential for "residualization" of services for excluded groups, as offline channels are run down or even withdrawn altogether (Margetts, 2010, p. 12).

Were disability organizations to rely largely on the Internet to communicate their messages they may reach those online but exclude others whose connections or computer skills combine to restrict their access to the Internet.

Further research is required in order to establish whether the activities surveyed above do have any measurable impact on public awareness of the needs of people with disabilities and the wished-for enactment of policy by Government and its agencies at national and local levels.

At this point it is clear the disability organizations are active in self-presentation on the Internet and in using it as a tool to motivate and organize their members to become politically active in creating pressure towards changes to Government policy which would benefit disabled people.

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<u>APPENDIX</u>

The Use Of The Internet By Disability Organizations In Influencing Policy

<u>Please complete this questionnaire by using the reply button to this email and</u> <u>choosing the letter of the response you favour and typing in your examples after each</u> <u>question.</u>

What is the name of your organization?

<u>Please type your answer here:</u>

What is your position in this organization?

<u>Please type your answer here:</u>

1. Does your organization consider that government policy and practice could be improved to better the lives of the group of people you represent?

A. Very much B. Somewhat C. A Little D. Not Much E. Not

<u>at All</u>

Please type your answer here:

Please give some examples of such improvements your organization is working towards. Add these examples here:

2. Does your organization use the Internet to attempt to influence government policy (national or local) with regard to people with the disability your organization represents? Type in Yes or No here If No, go to Q5:

If Yes: How? Please type in some examples here:.

3. Please give some examples of how you have used the Internet to successfully influence government policy (national or local; please describe the policy). Please type your examples here:

4. Do you invite people to comment on your website about matters that affect the

<u>group you represent?</u> <u>Type in Yes or No:</u> <u>Are these comments helpful?</u> <u>Type in Yes or No and if possible give an example</u>

5. Are there ways other than the Internet that you use to attempt to influence government policy? Please give some examples. Please type your examples here:

6. Do you use the Internet to attempt to influence government agencies (e.g., Office for Disability Issues and other agencies)? Type in Yes or No If Yes, please give some examples. If No, go to Q9.

7. To what extent do you think you have been successful in influencing government policy? (Tick one box)

A. Very much B. Somewhat C. A Little D. Not Much E. Not at All

Your answer:

8. Which do you think is more likely to influence government policy -- lobbying directly (e.g., MPs, Heads of agencies) or via the Internet? Please type your answer here:

9. Do the activities of your organization on the Internet get picked up by the media (press and/or television)? Type in Yes or No: If No, go to Q 12.

If Yes, please give some examples. Please type your examples here:

10. Is such media publicity helpful?

A. Very much B. Somewhat C. A Little D. Not Much E. Not

<u>at All</u>

Your answer:

<u>11.</u> Do you run joint campaigns using the Internet with other disability organizations? <u>Type in Yes or No:</u>

If Yes, please give some examples.

<u>Please type your examples here:</u>

Any other comments you wish to make?

<u>Please type your comments here:</u>

Thank you for your help.

Des & Mary Power