Effective consumer consultation in the planning and delivery of health and social services a New Zealand case study

A comparative study of the theory and practice of government organisations in engaging consumers in consultation

A research project submitted to Victoria University for partial fulfilment of a Master in Communication degree by Julz Britnell

Contents

Abstract

About 600 million people in the world live with disabilities (World Health Organisation, 2007). Over the past ten years there has been increasing calls for government organisations in the health and disability sector to involve consumers in their decision-making, service design and general governance. This has led government health and disability organisations in different countries to try and find ways to ensure consumers are consulted with and involved in decision-making processes (Coney, 2004).

The potential benefits of effective consumer consultation are better quality services, policy and planning decisions that a more consumer focused, improved communications and greater ownership of the local health services. For consumers effective consultation can mean they get better outcomes of treatment and support, a more accessible and responsive service and improved health. For the community consultation can help bring about a reduction in health inequalities and provide a health service better able to meet the needs of its constituents (Anderson et al., 2002).

There are a number of real and perceived barriers to consumer consultation. Consumers may be anxious that their views will not be taken seriously, that they will look foolish or that they won't understand what's being talked about. Staff and organisations might be anxious that their work will be criticised, that there will be unrealistic demands to change services or that their role and authority might be undermined (Fletcher & Bradburn, 2001). For consultation to work there needs to be commitment from the organisation to plan and provide adequate resources. Developing a strategy is critical before organisations start down this path. The UK Audit Commission (2003) believe developing a strategy will help organisations to define exactly what the purpose of the consultation is, what they want to achieve, help them identify the relevant stakeholders and assess what level of engagement to undertake.

Consultation is an important part of designing, delivering and managing effective health and social services. There are many different ways of engaging consumers and finding the right way for each organisation takes planning, commitment, time and energy.

Chapter One - Introduction

1.1 Research Question

Currently Disability Services at the New Zealand Ministry of Health consults with the public through an annual round of national consumer forums and through their Consumer Consortium – made up of 18 people with a range of disabilities. Involving disabled people in planning and delivering services can be a difficult process and is one that requires research and planning to get the best outcomes.

The question this research project is answering is 'How Disability Services of the New Zealand Ministry of Health can effectively engage disabled people in the consultation process'.

This project will help us to gain greater understanding of disability and of the national and international legal frameworks governing disability. It will also help us to identify best practice in consulting with consumers and explore the use of the various communication technologies to improve communication between disabled people and Disability Services of the New Zealand Ministry of Health.

The writer is part of the project group reviewing consumer participation for Disability Services in the Ministry of Health. The outcomes of this research will be used to review the Consumer Participation Plan, as part of a wider Stakeholder Consultation Strategy.

1.2 Background

About 600 million people in the world live with disabilities of various types. Of this total, 80% live in low-income countries, most are poor and have limited or no access to basic services, (World Health Organisation, 2007). The number of disabled people is increasing due to the ability to manage the rise of chronic diseases, injuries, accidents and violence. Life expectancy has increased particularly in developed countries and technological advances means that many more people are surviving accidents and able to be kept alive when previously this may not have been possible.

Health and disability services planning takes on increasing importance as rise in demand for services are not always matched with an equal rise in funding. As such, effective use of the available funding to get the best outcomes for consumers is a high priority.

Sandra Coney (2004) says that over the past ten years there have been increasing calls for New Zealand government organisations in the health and disability sector to involve service users in their decision making, service design and general governance. This trend of increased consumer involvement is evident internationally also and has led government health and disability organisations in different countries to try and find ways to ensure consumers are consulted with and involved in decision-making processes. In the UK public involvement has been increasingly written into government health policy (Anderson et al., 2002). Coney (2004) says that the way in which different countries have addressed this has depended on the way their health system is configured and owned, their political systems and their socio-cultural norms.

New Zealand has a long history of community involvement in health, resulting in a large number of health services being initiated outside of government (Coney, 2004), and with the emergence of strong health and disability advocacy groups the call for greater involvement has gathered pace. Disabled people have often been under-represented in consumer consultation, with limited understanding of the different disability types and the unique cultures and needs of each group (Coney 2004).

In 2001 the New Zealand Disability Strategy (NZDS) was put in place. This strategy guides government action to promote a more inclusive society. The NZDS is a framework that ensures government agencies consider and consult with disabled people before making decisions about them and for them. The NZDS also aims to ensure that disabled people enjoy the same rights and responsibilities as other members of their community.

Since the NZDS was established in 2001, government organisations in NZ have been challenged to address the needs of disabled people in the consultation process. There are different interpretations of what consultation means. The New Zealand Health Strategy (2000) states that, "consultation is a process of seeking the views of

others…not equivalent to merely providing information…includes listening to what others have to say…must be genuine".

On December 13, 2006 The United Nations (UN) General Assembly adopted a UN Convention on the Rights of People with Disabilities. This is the first official recognition of disability as a human rights issue. International law now recognises the full rights of disabled people to enjoy the same economic, social, political, cultural and human rights as enjoyed by all other citizens (UN Convention on the Rights of People with Disabilities, 2006). On 30 March, 2007, the convention opened for signature and ratification. Ratifying countries will be legally obliged to treat disabled people as individuals with rights (Inclusion Europe, Dec 2006).

1.3 Methodology

To answer the research question I will do a review of New Zealand and overseas literature to identify what legal requirements and processes are currently in place around the rights and responsibilities of disabled people. I will identify which elements (including attitudes, behaviour and information technology) are necessary for effective consultation with disabled people. I will then look at how different countries approach consultation, what tools they use and how effective they are.

I have chosen to study four countries in addition to New Zealand as they have a similar understanding of consultation and participation, are members of the UN and are all on the same pathway, although at different places, to increasing consumer participation in the planning and delivery of health and disability services; Australia, Canada, United Kingdom and the United States.

1.4 Definitions

Impairment – "any loss or abnormality of a psychological or anatomical structure or function". Impairments are disturbances at the level of the organ, (International classification of impairments, disabilities and handicaps – World Health Organisation, 1980).

Disability – "any restriction or inability (resulting from an impairment) to perform an activity in a manner or within the range considered normal for a human being". This

describes a functional limitation or activity restriction caused by an impairment. Disabilities are descriptions of disturbances in function at the level of the person, (International classification of impairments, disabilities and handicaps – World Health Organisation, 1980)

Handicap – "any disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfillment of a role that is normal for that individual". The classification of handicap is a classification of circumstances that place individuals "at a disadvantage relative to their peers when viewed from the norms of society". The classification of handicap deals with the relationship that evolves between society, culture and people who have impairments or disabilities, as reflected in people's life roles, (International classification of impairments, disabilities and handicaps – World Health Organisation, 1980)

Disabled person - someone with a long-term physical, intellectual, sensory or age related disability (or combination of these) that results in a reduction of independent function and will require ongoing support, (Ministry of Health, New Zealand).

Consultation - a process of seeking the views of others. It includes listening to what others have to say and considering responses, it must be genuine and allow sufficient time for the process. Those seeking consultation must keep an open mind and be ready to change/adjust plans as necessary. Consultation is the statement of a proposal not yet fully decided on, (The New Zealand Health Strategy, 2000).

Participation - is an umbrella term including different means for consumers to directly participate in political, economic, management or other social decisions, (Wikepedia, 2007).

Inclusion - is a "political and social struggle to enable the valuing of difference and identity". It focuses on assimilating into the already existing. Regardless of how inclusion is defined, the general goal is toward providing more opportunities for those with and without disabilities to spend time together, (Rice, 2006).

Inclusion and participation are essential to human dignity and to the enjoyment and exercise of human rights. They should be reflected in the development of strategies that seek to bring about a genuine equalisation of opportunity, (Rice, 2006).

Inclusive community - an inclusive community means that communities adapt their structures and procedures to facilitate the inclusion of people with disabilities. The community takes responsibility for tackling barriers – beliefs or attitudes, policies or laws, physical barriers or inaccessible transport, (World Health Organisation, 2004)

Accessibility - can be summed up by saying that anyone can get a full and complete understanding of the information presented, (Section 508 Americans with Disabilities Act, 1990).

Partnership – when a number of different interests will only come together formally or informally to achieve some common purpose. They do not have to be equal in skills funds or even confidence but they do have to trust each other and share some commitment, (Wilcox, 1994).

Stakeholder - any organisation, government entity, or individual that affects or may be affected by the organisations actions, (Wikepedia, 2007).

Stakeholder Consultation Strategy - strategy developed for Disability Services to help identify stakeholders and guide, plan and implement a programme of meaningful consultation.

1.5 Scope

Although this research is primarily interested in disability specific information, the scope has been extended to cover a broader definition of health and social care/services. Much of the literature looks at consultation at this broader level with disability being one factor to be taken into consideration. While all of the countries studied had some kind of office on disability or disability issues these services did not deal directly with the planning and funding of services rather they had more of an advocacy role. Planning and funding for disability services came under the banner of human services, health, families and social care.

Chapter Two - Literature review

2.1 Theoretical and Regulatory Frameworks

2.11 Legal frameworks

There are a number of international and country specific legal frameworks that cover disability. All of these frameworks cover the role of consultation and participation of disabled people in the decision-making process. Each country studied has taken a different path to legally protect the rights of disabled people.

United Nations (UN)

The UN Overview of International Legal Frameworks for Disability Legislation (2007) identifies the main disability specific nonbinding international Instruments:

- Declaration on the rights of disabled persons (1975).
- World program of action concerning disabled persons (1997).
- Standard rules on the equalisation of opportunities for persons with disabilities (1993).
- Sundberg Declaration on actions and strategies for education prevention and integration (1981).

International treaties are binding on United Nation State parties (States) and create legal obligations of these States. All international human rights instruments protect the human rights of persons with disability as well as all other citizens of that country.

The UN states that declarations and rules are nonbinding but are useful for interpreting international standards and implementing them in national legislation. International instruments such as declarations, resolutions, principles, guidelines and rules are not technically legally binding. They express generally accepted principles and represent a moral and political commitment by each State. They can also be used as guidelines in enacting legislation and formulating policies.

The UN identifies that translation from an international convention, standard or norm to national law and then to local implementation is slow and complex but fundamental.

They identify three main methods that are available to implement international legal instruments in domestic law:

- Direct incorporation of rights into what may be termed a Bill of Rights
- Enactment of different legislative measures in civil, criminal and administrative laws
- Self-executing operation.

(UN Overview of International Legal Frameworks for Disability Legislation, 2007)

The UN International Norms and Standards Relating to Disability (2003) identify two points relating to the disability framework that are specifically relevant to this research,

Awareness raising

States should take action to raise awareness in society about persons with disabilities. States should also distribute information on available services and programs that would reach all concerned disabled persons as well as the general public. Information should be available in forms that can be used and understood by people with visual, hearing or other communication limitations. Persons with disabilities and their families should be involved in the making of public information and education programs.

Policymaking and planning

States should ensure that disability aspects are included in all relevant policy-making and national planning. Rule 14 in the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities states action should be stimulated and supported by member States. Communities should be encouraged to develop programs and measures for persons with disabilities. States should involve organisations of persons with disabilities in all decision making and direct contact with them should be established. This way the organisations can influence government policies and assertions in areas that concern them.

The greater the extent to which the international norms on disability are widely known, the greater the possibility of domestic courts complying with these norms, (UN International Norms and Standards Relating to Disability, 2003).

There are a number of different frameworks, strategies and/or Acts of Parliament that different countries have enacted around disability. The UN Convention on the Rights of People with Disabilities, which was adopted on Dec 13 2006, is one of the most significant pieces of legislature enacted in regards to disability as it marks a shift in attitudes and behaviour towards disabled people (UN enable, 25 May 2007). Whilst this is not the first legal statute that has been enacted, other pieces of legislature have related to specific issues such as disabled peoples right to work, discrimination against disabled people, protection of the rights of disabled children and those with intellectual disability, not to the basic human rights of all disabled people as citizens.

New Zealand

The Health Act 1956 states that in order to ensure that the views of consumers are heard, the Public Health Group shall institute a programme of regular consultation with such members of the public and other persons considered appropriate (Section 3F Health Act, 1956).

The New Zealand Public Health and Disability Act (2000) requires District Health Boards to consult their resident populations on the significant aspects of district strategic plans before determining or amending those plans.

The New Zealand Health Strategy was published by the Ministry of Health in December 2000 as a framework within which District Health Boards and other organisations across the health sector will operate. It highlights government priorities in health.

New Zealand Disability Strategy (NZDS) was published by the Ministry of Health in April 2001 'as a framework to ensure that all government departments and agencies consider the needs of disabled people before making decisions' (New Zealand Disability Strategy foreword, 2001).

Australia

Australia has a number of different frameworks in play depending on which state you are in. National frameworks are:

- The Disability Services Act 1986, which was reviewed in 2006. This Act requires encourages service providers to consider the needs of disabled people when

they design and deliver services (An Overview of the Disability Services Act, 2006)

- The Commonwealth State Territory Disability Agreement (CSTDA) 1991 encourages organisations to consult with disabled people to find out what they need
- Intellectually Disabled Persons' Act 1986
- Disability Discrimination Act 1992.

Some states have also put in place other plans that attempt to address disability issues

- Victorian State Disability Plan 2002 – 2012 – one of the guiding principles is that of equality which recognises that disabled people are citizens who have the right to participate (Disability Services Guiding Principles, 2007)
- Disability Services framework 2004-2007 – South Australia
- Disability Framework for Action 2005-2010 – Tasmania
- Future Directions: A Framework for the Australian Central Territories 2004-2008
- Building Healthier Communities Framework for Health and Community Services 2003-2009

Canada

According to the Council of Canadians with Disabilities, since the passage of the Americans with Disabilities Act, Canadians have been advocating the passage of the Canadians with Disabilities Act. Discussions in the Ontario legislature about an Ontarian's with Disabilities Act, which was subsequently enacted in 2001, have fuelled the national demand for a Canadian Act to address the systemic discrimination faced by disabled people (Disability Task Force, 1996). A five-year timeline was put in place for implementing a Canadians with Disabilities Act in October 1996. It is still not in place.

In Unison: A Canadian approach to disability issues (1998) excluding the Government of Quebec, describes the vision and long-term policy directions of the Canadian Government to promote the full citizenship of disabled people in all aspects of Canadian society, based on the values of equality, inclusion and independence (In Unison, 1998).

United Kingdom

The Disability Discrimination Act 1995 gives disabled people rights in the areas of employment, education, access to goods, facilities and services and allows the government to set minimum standards. It was amended in 2005 to include requiring public bodies to promote equality of opportunity for disabled people (Disability Discrimination Act, 2005).

Section 11 of the Health and Social Care Act 2001 places a duty on National Health Service Trusts and Primary Care Trusts to make arrangements to involve and consult patients and consumers in the planning and development of health services, and in how the services operate (A Stronger Local Voice, 2006).

United States

The Americans with Disabilities Act (ADA) 1990 "guaranteed disabled people equal opportunity in employment, state and local government services, public services, transportation and telecommunications. It ushered a dramatic change in attitude towards people with disabilities. As a result people with disabilities were empowered to participate meaningfully in society to an extent never before possible", (Section 508 of the Rehabilitation Act).

2.12 Theories of communication

To help improve communications between Disability Services and disabled people phenomenological, sociopsychological and sociocultural theories, that explain communications processes, will be explored in this study. If we look at a basic Shannon Weaver model of communication we see how information goes from one person to another. Ideally whatever the information sent is what arrives at the other end.
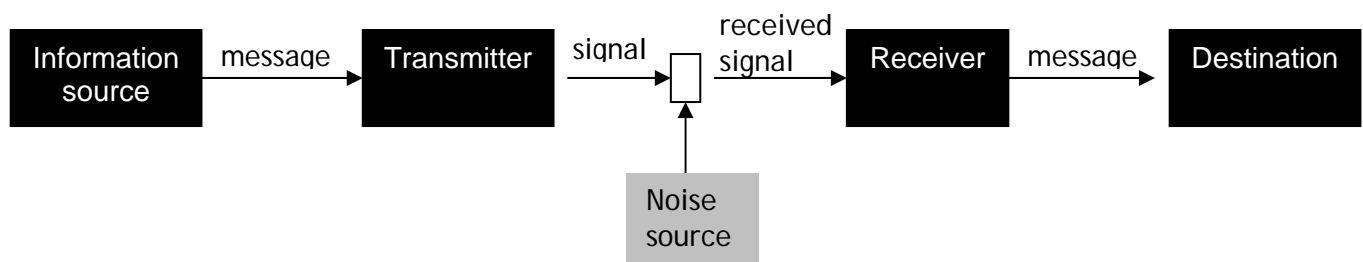

Fig 1. Shannon Weaver Model of Communication, 1947.

The Shannon-Weaver model proposed that all communication must include six elements: a source, an encoder, a message, a channel, a decoder and a receiver. However it is a linear model and in order to ascertain the accuracy of the message that gets through there needs to be some kind of feedback.
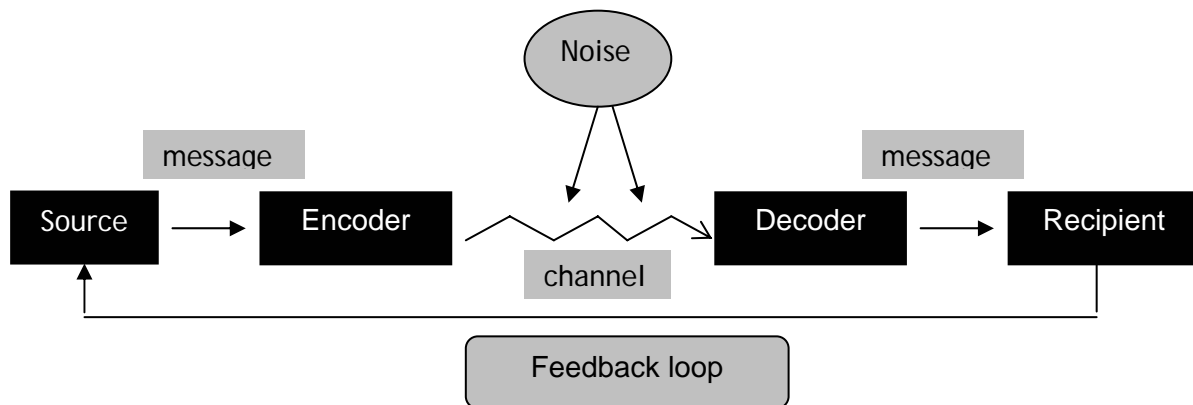

Fig 2. Updated Shannon-Weaver model with feedback loop.

However a number of things can change the effectiveness and accuracy of the communication. A number of theorists have looked at what can cause interference in a message getting through intact such as attitudes, beliefs and frames of reference.

Charles Osgood (1963) discusses theories on *Message Reception and Processing.* He looks at message interpretation and meaning and what associations/meanings people have with certain words, how these meanings are learned and how they relate to thinking and behaviour. Within both Disability Services itself, the disability sector and consumers there are a number of pre-existing associations/meanings that people have with commonly used words such as disability, government, health and consultation.

In figure 3 we see how a physical stimulus such as a meeting triggers an internal response which leads to an internal stimulus and this is reflected in the person's outward response.

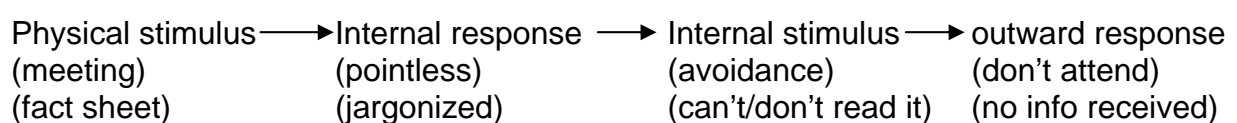| Physical stimulus	→	Internal response	→	Internal stimulus	→	outward response
(meeting)		(pointless)		(avoidance)		(don't attend)
(fact sheet)		(jargonized)		(can't/don't read it)		(no info received)

Fig 3. Meaning as Internal Representation, Litlejohn, 2002.

Perceived and actual causes of behaviour are explored by Fritz Heider (as quoted in Littlejohn, 2002, p 120) in *Attribution Theory*. Heider elaborates on several types of causal associations that people commonly make. *Situational effects* means behaviour is affected by the environment, where consumers may find the environment they're being asked to enter supportive or difficult (such as inaccessible venues, attitude of organisers) which will affect how they behave. *Personal effects* is where behaviour is affected by the ability to influence things personally. Consumers may wonder whether their input will make any difference.

A person's attitude toward some object is a function of the information (beliefs) s/he has about the object (Fishbein, 1975). The *Information Integration* model looks at how information is integrated or combined in the formation of attitudes. All information has the potential to affect attitudes whether this information supports or refutes your beliefs will influence whether it is seen as a positive or negative (Littlejohn, 2002). Attitudes are also affected by whether you believe the information to be true or not, valuable or not and therefore the weight it is given (Fishbein, 1975). Attitude is a crucial focus point for disabled people (NZ Federation of Disability Information Centres, 2006). If consumers do not believe that Disability Services is committed to talking with them and/or they do not agree with the information that is being disseminated or discussed, then it will be difficult to engage with them effectively.

Muzafer Sherif (1965) tells us that judgements involve comparison and that there will always be a preferred option or position to which the person is personally committed. This preferred option is a major anchor. In his *Social Judgement Theory*, he says that people make judgements on the basis of these anchors or reference points. In social perception (communication) anchors are internal and based on past experience. The internal anchor is always present and influences the way a person responds to messages. The more important the issue to one's ego the more strongly the anchor will influence what is understood (Littlejohn, 2002, p 130). The concept of participation and consultation is likely to be a preferred option for disabled people. However, past experience of government consultation will affect their judgement of wherever this is a valuable process.

Judee Burgoon (as quoted in Littlejohn, 2002, p135) expands on interaction theories with her *Expectancy Violations Theory.* This theory states that communicators adapt and adjust their behaviours to one another. We have expectations about the behaviour of another person based on social norms as well as our previous experience and situation. It is suggested that with a long history of consultation between government and consumers, there are expectations in place already of how each party is going to behave.

Sanjay Pandey and James Garnett (2006) believe that while a primary executive function is to develop and maintain a system of communication, blockages in the communication system is one of the most serious problems in public organisations. They say the costs of government communications is often easier to measure than the benefits and that effective communication requires effective performance in interpersonal, internal and external communication.

2.13 Consultation

What does consultation mean?

In this study the words consultation, participation and public involvement are used somewhat interchangeably as they are in much of the literature. In this report I am using consultation/public involvement as the broader term for the process of engaging consumers in some kind of dialogue and participation used to talk about the degree of involvement in the consultation process e.g. information sharing process or consumer ownership of the process.

Consultation and participation is essentially about relationships (Trevor Gay,2003). Cheryl MacPherson (2006), states that stakeholder consultation is, "part of the democratic process, embraces respect for persons and is necessary for upholding the principal of justice". She believes that people are more likely to uphold standards they have participated in setting and that local ownership and leadership of stakeholder consultation is a form of capacity building.

Will Anderson et al. (2002), feel that public involvement is principally value driven. That people pursue it because they believe in both the process and the outcomes and that it

is usually a negotiation. Different stakeholders have different ideas about what public involvement can achieve and for whom. In practice, the outcomes of public involvement work are wide ranging, complex and often unexpected.

In their 2002 report *Keys to Partnership,* Anita Cameron et al. identified a number of incentives to get consumers involved. Consumers may want to be an agent for change, gain a greater understanding of the structure and functioning of social care organisations, develop networks, undergo training and/or have access to resources.

What counts as public involvement?

Definitions of public involvement are dynamic. If public involvement is defined too narrowly as a collection of methods rather than a range of relationships, then current practice can be undervalued, (Anderson et al., 2002). They believe that every public voice has value however, information and education are necessary. David Wilcox (1994) says that public involvement varies according to its purpose, the consumers involved, the degree of involvement, the methods employed to support this involvement and the context.

Christine Farrell in her 2004 report for the UK Department of Health, *Patient and Public Involvement in Health*, believes there is low public awareness of what public involvement is. She says that there are those that believe the tax-paying public should be fully involved, those that think they should be involved to a limited degree, those that think they should be kept informed and finally those who think involving taxpayers at all makes the system more bureaucratic and more complicated.

Participation

A model, or ladder, that describes different levels of participation and defines what kind of relationships reflect actual participation was developed by Sherry Arnstein in 1969. The Arnstein Model of Participation has been widely used as the starting point for research, and forms the foundation stone for much of the thinking around participation.
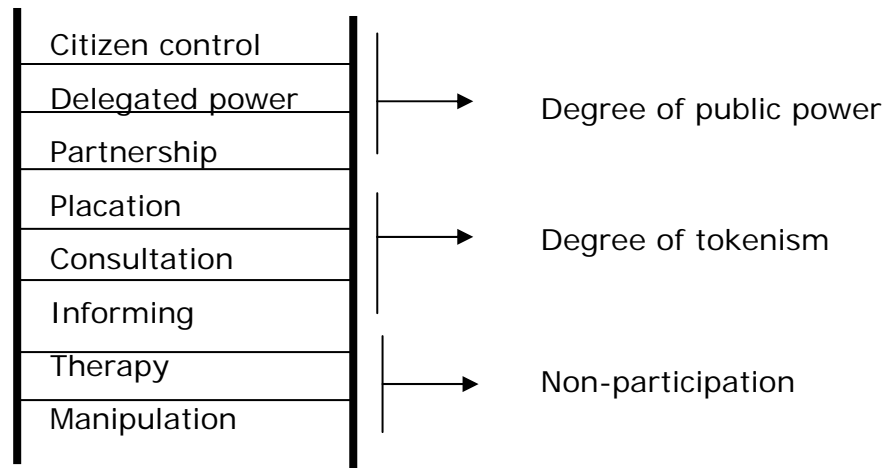
Fig 4. Arnsteins' ladder of participation, 1969.

Arnstein believes that the first step towards actual participation starts at *informing*. However, she feels that too frequently the emphasis at this level is on one-way flow of information with no channel for feedback. The *placation* step allows consumers to advise or plan but retains the power holders right to judge the legitimacy or feasibility of the advice. She believes it is only when we get to the *partnership* level that we see actual participation starting to take place. At the partnership level, power is redistributed through negotiation between consumers and the power holders. Planning and decision-making responsibilities are shared. When consumers hold a clear majority of seats with delegated powers to make decisions this is called the *delegated power* level. Finally, when consumers have control, handle the entire job of planning, policymaking and managing a programme, we have reached the top of the ladder, citizen control.

Wilcox (1994) adapted this framework in his research to five core areas. Supporting independent community initiatives, acting together, deciding together, consultation and information.
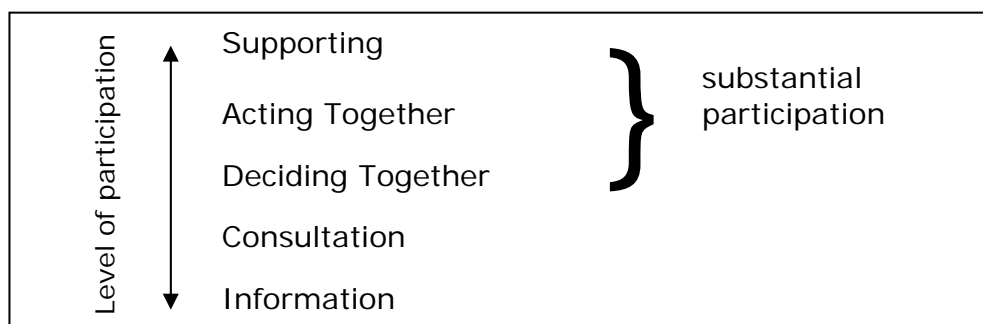

Fig 5. Wilcox's model of participation, 1994.

He says that when you *Support Independent Community Initiatives* you help others to do what they want and the process is owned by and moves at the pace of those who are going to run the initiative. He believes it is appropriate when there is a commitment to share power among individuals or groups in the community and people are interested in starting and running an initiative.

When you *Act Together* the different interests decide together what they want to achieve and they form a partnership to carry it out. Wilcox (1994) notes that there is usually a common language, a shared vision and the means to carry out the chosen approach. This process involves trust, takes time to develop and everyone needs to feel they have a fair say and chance of achieving what they want. This approach is appropriate when one party cannot achieve what they want on their own.

Wilcox (1994) states that *Deciding Together* is when you encourage others to provide some additional ideas and options and join in deciding the best way. It means accepting other people's ideas, choosing from the options that have been developed together. It is appropriate when it is important that other people own the solution.

When you *Consult* you offer a number of options and listen to the feedback you get. It means giving people restricted choice and is appropriate when you want to improve a service, you have a clear vision and plans to implement a project or program, the initiator can handle feedback and is prepared to use this to modify it options.

Finally, Wilcox (1994) says *Information* or telling people what is planned, is appropriate when you have no room to manoeuvre and must follow one course of action, when the action is essentially internal and does not affect others, or at the start of a consultation or other process.

Hilda Bastion (1996) used Arnstein's framework also as a basis for her description of participation.

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WIDE PARTICIPATION
Consumer representatives representing consumer's views
Consumers widely consulted and participating                    Active

OPEN INVOLVEMENT
Consumer representatives representing consumer's views
Consumers possibly consulted


RESTRICTED SCOPE
Experts advocating their perception of consumer's views
Possible token 'consultation' with consumers                   Passive.
                                                                Source or
                                                                recipient of
MANIPULATION                                                    information.
Consumers educated                                             Little effect on
                                                                the event.
NONE
Consumers perspectives and concerns not specifically
addressed
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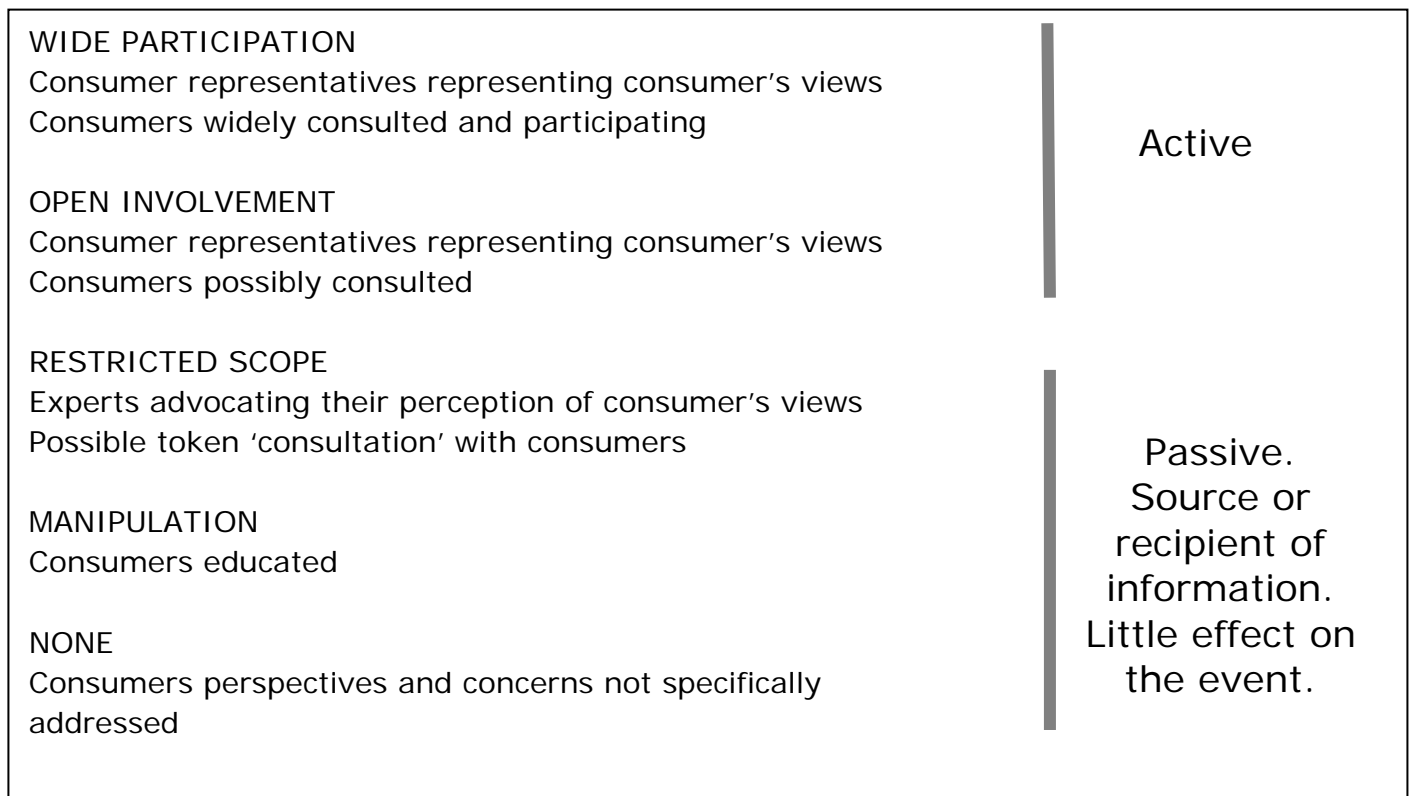
Fig 6. Bastion's participation framework, 1996.

ES Nilsen et al. (2006) simplified Arnstein's Ladder of Participation into three steps - consultation, collaboration, consumer control. *Consultation* was defined as asking consumers for their views and using these views to inform decision-making. *Collaboration* was described as active ongoing partnership with consumers. *Consumer control* was described as consumers designing undertaking and disseminating the results.

As we can see Wilcox (1994), Bastion (1996) and Arnstein all follow the same concept that the level of participation differs depending on the outcomes wanted and that there is a significant difference between giving information and meaningful participation.

Partnership
In their 2002 report *Keys to Partnership,* Cameron et al. identified that partnerships take time and effort to develop and that nurturing and sustaining partnerships requires energy and commitment. They believe a partnership is unlikely to work well if it is imposed rather than developed with people and that organisational culture and personal

behaviour have a big influence on a partnership. They felt that the real challenge was about getting the right culture and organisational behaviour rather than focusing only on structures and that a partnership has to be seen to deliver positive outcomes that are agreed by all agencies.

They also identified a number of components that can help ensure a partnership works. An organisation needs to find a way of engaging disabled people and other local people in ways that make sense to them, they need to promote ownership and have joint systems in place for workforce development, training, monitoring performance and planning activities. There also needs to be accessible, useful information and other supports available, (Cameron et al., 2002).
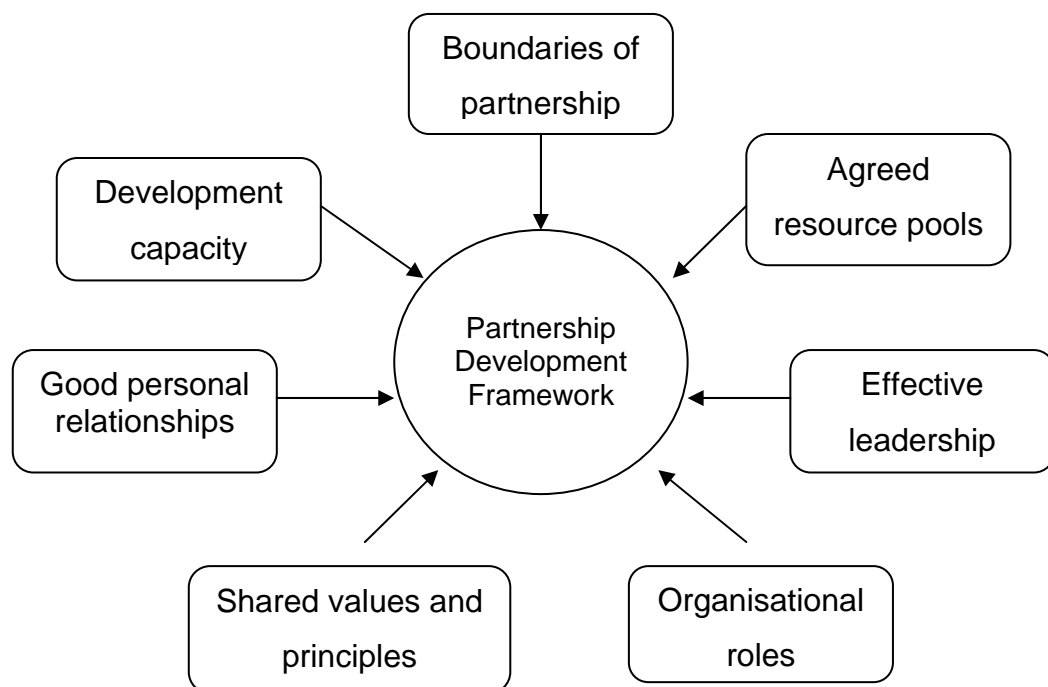

Fig 7. Keys to Partnership, 2002.

Wendy Bonser et al. (2003) agree that there are a number of steps that need to be taken to help achieve and maintain a successful relationship with consumers. Their guide stated that there is a need to recognise the role of public representatives and that the organisation may need to undertake staff development to increase their understanding of this. The organisation then needs to identify opportunities to engage public representatives and establish communication channels. Before the first consultation occurs the organisation needs to ensure the administration and structure of

meetings can accommodate any specific needs of the participants including using terminology and language that can be understood. Finally, there needs to be a commitment to undertake and disseminate evaluation outcomes.

Consultation Process

The UK Department of Health in their 2005 report *Involving Patients and Carers* explored three dimensions of a consultation process

1. Level of participation (as discussed above)
2. The process – the initial idea to consult, what process/approach will be used, which participation tools will be engaged and how it will all work
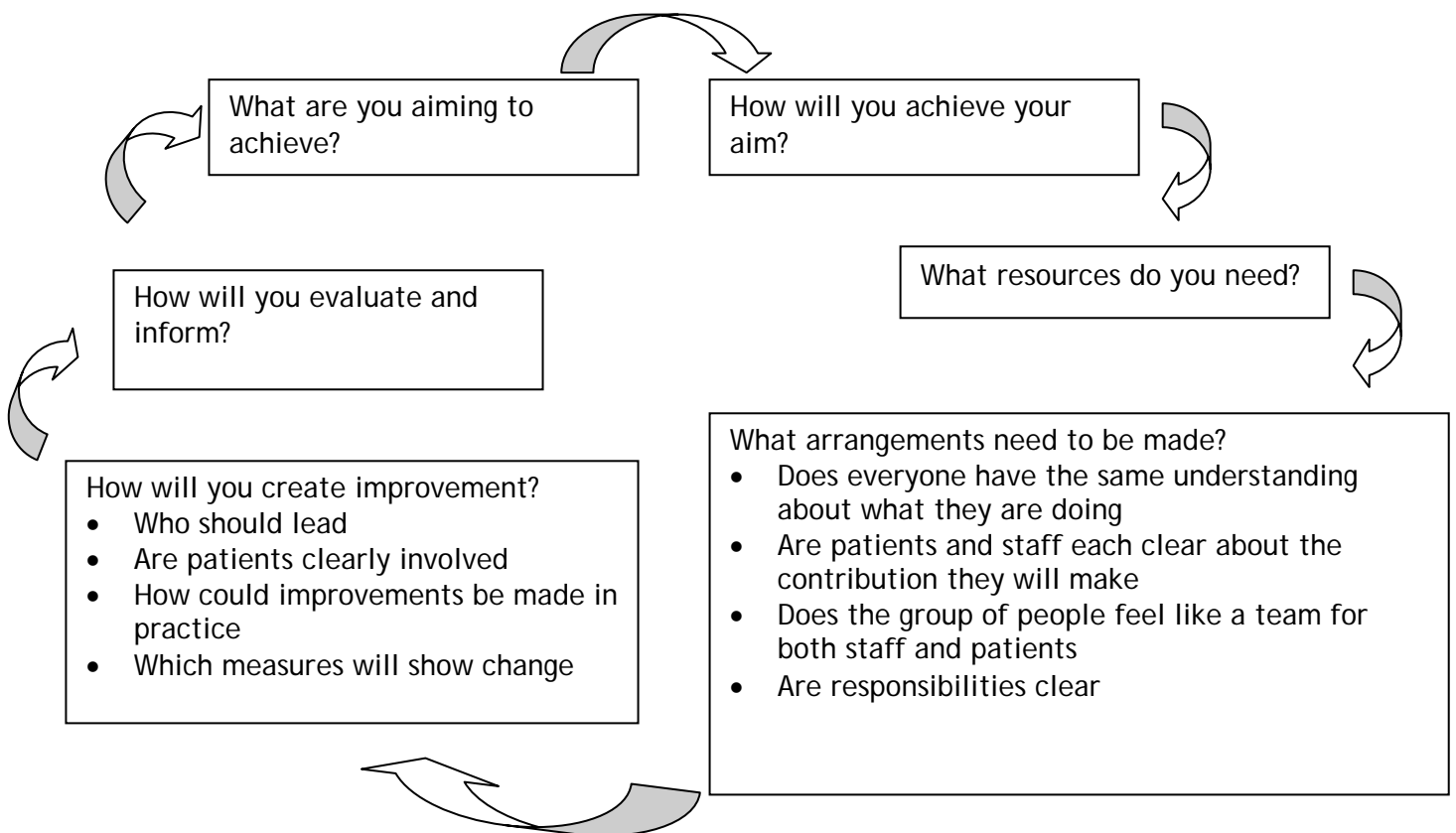3. People – who is involved?

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What are you aiming to          How will you achieve your
achieve?                        aim?

                                              What resources do you need?

How will you evaluate and
inform?
                                What arrangements need to be made?
How will you create improvement?   • Does everyone have the same understanding
  • Who should lead                   about what they are doing
  • Are patients clearly involved  • Are patients and staff each clear about the
  • How could improvements be made in   contribution they will make
    practice                       • Does the group of people feel like a team for
  • Which measures will show change   both staff and patients
                                   • Are responsibilities clear
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Fig 8. Involving Patients and Carers, 2005.

The UK Department of Health say any form of involvement must lead to demonstrable benefits to consumers, involving consumers at every stage.

Planning public involvement is an ongoing negotiation. In *Every Voice Counts*, the Scottish Consumer Council recommends a planning cycle with five key elements:

- Development of a vision
- Collaborative development of strategy
- Audit of current practice
- Development and support of a range of activities
- Monitoring, evaluation and feedback

2.2 Technology

Today meaningful participation in society requires access to a full range of information technologies. In the last decade technology has brought enormous changes to society as a whole. One challenge posed by the information revolution is to ensure that the promises of technology are available to all including disabled people. Information technology can empower the lives of disabled people if it is accessible or further segregate them from mainstream society if it is not, (US Department of Justice, 2004).

In their 2004 report, *Accessibility for People with Disabilities in the Information Age*, 2004 the US Department of Justice identified that a blind user can independently order groceries online and have them delivered to their door, and a person with cerebral palsy can fill in an online form for government services. Screen readers read aloud the text that appears on a computer screen or by converting the text on a screen into a series of raised pins in a Braille display. Speech recognition software lets users with limited dexterity use their voice to control their computer and closed captioning lets deaf users understand the content of television broadcasts and multimedia presentations. Some cars are now equipped with screen readers that provide audio navigation directions so harried drivers can focus on driving instead of reading paper maps. Speech recognition technology can now help those who never learned to type keep pace in a world where computers are increasingly common, (US Department of Justice, 2004).

The US Department of Justice says that many of these modern technologies that we now use were originally designed to provide disabled people basic access to the information than many of us took for granted. However, they also identified that

disabled people are most at risk of being excluded by society's advances if the technological innovations are designed without considering accessibility.

Those who choose to ignore accessibility when they design their products are at a substantial commercial disadvantage when they market the products to federal agencies. Because of these market forces accessible technologies are already becoming more widespread. The information technology revolution holds the promise of eliminating many of the historic barriers to disabled people, but it can also create new barriers if not properly designed (US Department of Justice, 2004).

2.21 Information and communication technologies
Martin Gould (2007) conducted research into whether there was a market for accessibly designed products, what factors influence this market and was there capacity within industry to design this way. According to the 2006 report *Digital Planet*, the global Information and Communication Technologies (ICT) marketplace was valued at US$3 trillion. The report projected that by 2009 it will be valued at US$4 trillion. Among the four major categories of ICT - hardware, software, services and communications, over half of the 2006 total ICT spending was on communications. China, India, Russia, Mexico and Turkey were the top five developing countries with the highest populations and highest overall market potential.

This research found that disabled users of information technology are often asked to pay high prices for phones with features that are not useful to them. There are rapid changes in technology often with decreased accessibility. Users are reluctant to adopt technologies that have proven frustrating in the past and they have difficulty finding devices that match their functional capabilities because of the lack of familiarity sales people have with accessibility features. Finally, users are reluctant to invest in technologies that have an unproven accessibility record. Gould (2007) believes that accessibility solutions must consider the needs of the individual with disabilities.

Gould (2007) also tells us that the groups at the highest risk of unintentional exclusion include disabled people, users with English as a second language, those in a non-native language location and those 65 plus years old. Designing with access in mind, otherwise known as 'universal design', can significantly increase the size of ICT markets

on a global basis. Consumers spend one out of every four ICT dollars worldwide. Per capita spending has increased every year since 2001 and in 2006 reached US$567. Therefore if we take the estimated 600 million disabled people worldwide there is a potential injection of around US$3.4 billion into the market by meeting the needs of this group of the community.

The findings from Gould's research were presented at the UN forum on inclusive ICT in New York in 2007. Some 200 representatives attended this forum from industry, government, academia and consumers. At the same forum, the UN News Center reported that the new array of inclusive technologies are bringing disabled people into the workforce and integrating them further into society. The UN News Centre says in its article *New Technologies Bringing Persons with Disabilities into Mainstream* that government regulations are helping to fuel this development. Canada now requires that 90% of TV programs be captioned and in the UK up to 5% of TV programs show a sign language translator. Japan, Mexico and Australia are preparing similar legislation to make TV more accessible (UN News Centre, 26 March 2007). Some of the discussions that took place highlighted that industry vendors should incorporate accessibility features from the start of the product development. A number of vendors are well intentioned but tackle the issue of accessibility too late in the product lifecycle. IBM, for example, incorporate feedback from disabled people into their software and hardware development from the start decreasing the costs associated with re-design further down the track. The forum also highlighted the importance of partnering with disability organisations within every country to try to make sure that solutions are relevant locally.

Information technology is rapidly changing the way we work, shop, communicate and play (Joel Kahn from the National Council on Disability, 2004). Like the UN forum, the council believes that designing with access in mind can significantly increase the size of targeted markets for IT. Every consumer is different and to remain competitive companies must learn to develop products that accommodate the wants, needs and preferences of as many individual consumers as is technically possible and economically feasible. The council says a sizable market for universal design products and services exists however, few companies seem to appreciate the size of the market or know how to tap the potential of it.

Kahn (2004) also believes that universal design may be achieved by making relatively minor modifications to the product design process currently used by manufacturers, although developers may not fully understand the needs of disabled users because disabled people are not usually integrated into the design process. He believes that government should use focus groups when developing standards and should include participation from a variety of consumers as well as individuals with technical knowledge. He also believes that industry should get disabled consumers involved early in the design process and always consult with the people they are designing for. Industry needs to recognise the advantage that can be had by building in universal design from the beginning. Like Gould (2007), the council believes designing with access in mind can significantly increase the size of the targeted markets and that good business practice dictates that designers and engineers avoid unintentionally excluding large populations of consumers from accessing and using the information technology they develop and manufacture.

2.22 Websites

Making Internet sites accessible to disabled people is not just a moral issue but also a business opportunity to tap into a larger share of the global market (UN News Centre, 4 December 2006). They report UN Secretary-General Kofi Annan, speaking at the UN International Day of Persons with Disabilities, as saying,

> Access to information and communication technologies creates opportunities for people, none more so than persons with disabilities. Moreover, as the development of the internet and these technologies takes their needs more fully into account, the barriers of prejudice, infrastructure and inaccessible formats need no longer stand in the way of participation.

At the same forum Frances West of IBM said, "You don't design accessible websites just for disabled people, but for all of us. Standards should be global not countrywide or region-wide", (UN News Centre, 4 December 2006).

The UN conducted a worldwide survey on websites for accessibility. The survey examined leading web sites for travel, finance, media, government and retail shopping in twenty countries including the UK, US, Australia, Asia, Europe, Africa and the Middle

East. Under the web content accessibility guidelines that the survey used, websites must allow users to easily adjust text size, navigate through the site, differentiate between colors, allow keyboard shortcuts and offer an alternative to JavaScript. The study found that only three out of the 100 leading web sites around the world meets the needs of disabled people and these were for the German Chancellor, British Prime Minister and the Spanish Government.

A report by the US Department of Justice on web accessibility, (Accessibility for People with Disabilities in the Information Age, Section 508 0f the Rehabilitation Act, Part II Web Accessibility, 2007), states that emerging technologies such as plugin's, scripts and applets create serious accessibility problems on many web pages. The report found that organisations do not consistently test their web pages using a text only browser, screen readers or other assistive technologies prior to posting. It also found that organisations do not consistently provide information to disabled users for using their web pages. While most web pages included text for non-text elements, a large number did not. The authors say the lack of alternative text poses one of the most formidable barriers to disabled users. The report also found that many web pages included data tables and pdfs that were not accessible. Finally, the report found that a large number of government forms were inaccessible, with no links to accessible alternatives.

The report says that designing accessible web pages is easy and that webmasters around the world, including the United Nations itself, should be aware that they are losing a significant portion of their intended audience by not being fully accessible. Disabled people shop, they travel and they need information just like everyone else. While disabled users are potentially the greatest beneficiaries of the information revolution, the survey results indicate that we are not even close to reaching the internet's full potential for use by disabled people. In addition to this given the use of the internet now by many government organisations to advertise consultation, provide submission and feedback information, for surveys and to encourage participation – not making them accessible seems ill-advised.

Chapter Three – Analysis of country specific consultation strategies

3.1 New Zealand

The NZ Health Strategy (2000) set some guidelines for consultation when it stated that 'District Health Boards will establish consultation processes whereby providers and users of services, and the community, will be able to have input into major decisions taken by the boards'. It went on to say that District Health Boards should encourage 'feedback from a range of people such as providers, health care users and the general public on a proposal it is considering'.

The NZ Health Strategy set down specific actions that should be considered by District Health Boards when consulting:

- Establishing a system to ensure the availability of useful and timely information on the board's processes and decisions
- Ensuring board members and 'liaison' staff are available to respond to issues
- Encouraging community health groups that will in turn have an established feedback loop with the board
- Consultation is not equivalent to merely providing information, nor is it equivalent to negotiation (consultation may occur without those consulted agreeing with the outcomes as implied in negotiation)
- Consultation includes listening to what others have to say and considering the responses
- The consultation process must be genuine and not a sham
- There must be sufficient time
- Boards must keep an open mind be ready to change and even start afresh
- Consultation should be about a proposal not a fully decided on plan.

District Health Boards also have particular responsibilities to ensure the participation of Maori by 'establishing and maintaining processes to enable Maori to participate in, and contribute to, strategies for Maori health improvements', (NZ Health Strategy, 2000).

The New Zealand Health Strategy (2000), goes on to say that you need to make sure that you consult with Maori, Pacific people, services users, caregivers and family, representatives from the community, consumer groups and other members of the

general public, and that consultation methods should reach those who may not be able to attend public meetings such as disabled people.

Sandra Coney (2004) identified a number of concerns consumers had when engaging in consultation. At times, they felt the consulting agency was unwilling to change its intentions and was therefore just 'going through the motions'. There was not enough time allowed for consultation and a lack of feedback about final decisions. There was a suggestion that the agency needed to have the right attitude and needed to clearly describe the purpose and effects of the consultation. Information needed to be accessible and distributed widely and there needed to be clear guidelines on how to make a submission.

Teresa O'Connor (2006) wrote a somewhat scathing article on the Nelson District Health Boards decision to engage in a consultation process around whether the board should continue to provide support services for intellectually disabled people. She claimed that the decisions had already been made to stop providing this service and that it was 'an exercise in futility'. O'Connor (2006) believes that the board has been involved in 'Clayton's' consultations for years, that decisions are made and then a consultation paper is put out to appease consumers. However, they provide very short time-frames making it difficult for people to respond and within the documents themselves allude to the fact that the decision has already been made.

So how do government organisations measure up? The Office for Disability Issues oversees the implementation of the New Zealand Disability Strategy (NZDS). Every quarter government agencies are required to submit what they are doing to achieve the objectives of the strategy. The 2006 Office for Disability report, *Work in Progress,* describes what activities have been undertaken over the past year. In its foreword Mike Gourley, President of the Disabled Persons Assembly, comments that while it is good to see an increasing number of government departments reporting initiatives that will improve the lives of disabled people there is still a long way to go. He feels that Maori and Pacific peoples do not feature as highly as they should on the various departments' agendas, education is still lagging and that progress is slow five years after the NZDS was put in place.

It is interesting to note that while 41 government agencies reported on what they were doing to implement the NZDS, only five actually reported engaging with disabled people, usually as part of an advisory group. While that's not to say the other agencies are not doing that, there is much talk of reviewing services and developing strategies without clear indication that disabled people are being involved in the process.

District Health Boards now have Disability Advisory Committees – although first hand reports on the effectiveness of these vary, (Consumer Forum Minutes, 2006). Disability Services of the Ministry of Health have a consumer consortium made up of 16 representative disabled people or parents. This group meets twice yearly to give input into the strategic direction, proposed work plan and project planning for Ministry of Health funded disability support services. A number of these members are also part of advisory groups for specific projects. It is interesting to note that a number of the same people appear on advisory boards for other government agencies as well. Disability Services also runs an annual round of consumer fora, hui and fono where they hold open meetings in cities and towns throughout NZ for disabled people, their families, whanau, aiga and carers to come along and feedback on what is working, what isn't working and how things could be improved. Feedback from these meetings and the consortium influenced the work priorities over the next three years and are reflected in the strategic and work plans, (NZ Federation of Disability Information Centres, 2006).

The Office for Disability Issues has been reviewing long-term disability support services. As part of this review, they are consulting with consumers about how people find out about and get disability services as well as how we can work together across government to make things better for disabled people, (Office for Disability, 2007). There is also currently a Social Services Select Committee inquiry into the quality and care of service provision for disabled people. Consumers, among others, were given the opportunity to make a written submission to this committee and indicate whether they would like to speak to it as well.

3.2 Australia

Under the Australian Governments Disability Service Standards, Standard Three emphasises "decision making and choice – having your say" while Standard Five covers "participation and integration – taking part in the community".

Mary Lindsay (2004) says that changing attitudes to disability by government has resulted in a range of policies designed to include people with disabilities in the wider society. The government's approach is intended to move the focus from services and service providers to individual consumers and their rights. Have these objectives been realised? Lindsay (2004) believes not. Lindsay (2004) does feel however, that the failure to translate rhetoric into reality does not lie solely with the government. She states that service providers, advocates and consumer organisations have thwarted some of the government's most innovative attempts to help people with disabilities and feels that these groups must therefore also take some responsibility for the government not achieving its objectives. The result is a complex, fragmented maze of services each with different administrative and funding arrangements, different target groups and each responsible to different levels of government. In the resulting confusion consumers are the losers (Lindsay, 2004).

The Commonwealth State Disability Agreement (CSDA) 1991 was developed to rationalise government roles and responsibilities to the funding in operation of disability services. Recent analysis by Lindsay (2004) suggests that it has failed to achieve its objectives. While it was hoped that the CSDA would improve consumer information and simplify services, consumers felt that there was inadequate consultation and that it was devised for administrative convenience rather than to help develop services that were integrated and complementary across agencies, (Lindsay, 2004).

Like NZ, Australian States report on their activities to implement the CSDA each year. The latest report, published in 2006, on activities that relate to consultation practices states that Australian Capital Territory completed a community participation review. The Queensland State Government implemented a new regime to strengthen their capacity to seek and receive community advice on disability issues and increase regional representation. The Queensland State Government conducted public consultation in 2002, 2003 and 2004 on the Disability Services Act. They also conducted a consumer

satisfaction survey, and consulted widely on *Have Your Say: On Improving Disability Services in Queensland*.

The South Australian State Government reports that it established a working party that provided parent representatives with the opportunity to have a say in the future direction of the "Moving On" programme. The Government of Tasmania reported it undertook extensive community consultation on the development of the whole of government disability framework, developed working relationships with stakeholders, local government, access advisory committees and disability services. While the Victorian State Government reported it conducted community consultation about the revamped disability bill and released a guide to improve consultation and communication with disabled people. Their Disability Advisory Council now only has disabled people and parents of disabled children on it

The Government of Western Australia reported that it conducted statewide consultations with disabled Aboriginal people, families, carers and service providers on *Access for Aboriginal and Torres Strait Islander People*. New South Wales was the only state not to specify they had engaged in consumer consultation.

Bastion (1996), when talking about the development of guidelines, says that in theory the Australian system involves public consultation and consumer involvement at all levels and draft guidelines should undergo a process of community consultation before final acceptance. She claims that most guideline development processes have thus far either had no participation or have enthusiastically embarked on a program merely to manipulate public opinion. Consumers commonly make an appearance in guidelines as recipients of professionals' perspectives. Bastion (1996) believes involvement should ideally begin at the start with setting the agenda and determining the players and their roles. However, she discovered that some guideline developers did not seem to see consultation as an integral part of the whole process, but rather as an add-on along the way.

Bastion (1996) does feel that the idea that consumers may be important players in the process of guideline development is spreading although it still faces some resistance.

She reports that some believe it is a scientific assessment and therefore do not see the need for consumers opinions. She also states there is the belief that consumers cannot be as objective as a professional. Health professionals are concerned that the result could be politically correct at the expense of appropriate medical care. Bastion (1996) reports that one doctor stated 'when certain non-physicians are put on the team for political reasons it diminishes the credibility of the guidelines at least in the doctors' eyes'. She feels that some people simply believe that consumer participation has a cosmetic purpose only, and that 'it is the antithesis of science that could lead to lower professional standards'.

Gavin Mooney and Scott Blackwell (2004) say there is growing interest in involving consumers in decisions about health care provision. In contrast to some of the people Bastion (1996) spoke with, they found that when consumers were asked to take community focus, were presented with balanced evidence and given time to discuss and deliberate, they were able to identify and debate issues of broad principle and make rational decisions.

They also found that health care spending decisions made within budgetary constraints were not generally made in close consultation with the community. Mooney and Blackwell (2004) felt that having consumer forums were a way of discovering community values and supporting informed decision-making. They found that through this process the community could give meaningful advice on board issues underlying health resource allocation and that they were capable of dealing with some big issues conceptually as well as practically. Mort and Harrison (as quoted in Mooney and Blackwell, 2004) commented that being in favor of public participation these days is rather like discussing a virtue, it's hard to find anyone disagreeing with the idea but many don't practice what they preach. Mooney and Blackwell (2004) believe that consultation is best at the level of determining principles rather then specific procedural processes where particular technical knowledge is needed.

Mooney and Blackwell (2004) stated that there were various problems with seeking community preferences: the time taken to achieve consensus, the difficulties in establishing informed choice and the tendency for pressure groups and interested parties to outweigh the silent majority. None of which, they believe, is insurmountable.

They feel the best approach will vary depending on the questions being asked, the community concerned and the resources available. However, they emphasised the need for good information and time to reflect.

3.3 Canada

The Government of Canada (Future Directions, 1999) believes that to address disability issues requires the cooperation of government, disabled people's organisations, disabled people and their families, and the private sector. In 1998 the Government of Canada and the provinces and territories, excluding the Government of Quebec, jointly released *In Unison: A Canadian approach to disability issues.*

The report identified that government policies and support programs had become complex and even confusing. It found they were inflexible and often discouraged or prevented disabled people from participating fully in the communities and workplace. A federal task force on disability issues was created to hold public consultations with disabled Canadians and seek their advice and guidance on future government action. From this consultation the Canadian Human Rights Act was amended to ensure that federal employers and service providers were supportive of and accessible to disabled people (In Unison, 1998).

One of the objectives of *In Unison* is to encourage greater participation. The report suggests the governments move to a new approach where rather than considering disabled people as recipients of care, dependent and passive they see them now as participants, with shared responsibility and integrated into the community.

One way *In Unison* identified this could be achieved was through building the capacity of the disability community by providing and supporting events and mechanisms which would encourage greater engagement, community deliberation and consultation. With *In Unison* the Government of Canada made a commitment to consult with disabled people, the provinces, territories, aboriginal representatives and community representatives to determine the priorities.

The Disability Task Force states that since the passage of the Americans with Disabilities Act in 1980, Canadians have been advocating the passage of the

Canadians with Disabilities Act. They claim that recent discussions in the Ontario legislature about an Ontario's with Disabilities Act, which was enacted in 2001, have served to fuel the national demand for a Canadian Act.

Straight.com (2006) reports that MP Peter Julien has drafted a private members bill to institute a Canadians with Disabilities Act, which he says will promote and enable accessibility to services for disabled Canadians. The article reports that Julien consulted with stakeholder groups on the proposed bill, most of who were strongly in favor of it. *In Unison* describes the setting up of a special committee to undertake a comprehensive review of federal legislation in 1981 and then in 1996 states a federal task force on disability issues was established which also organised public consultations throughout the country. *In Unison* reports that from this consultation a Canadian with Disabilities Act was viewed as the best mechanism for addressing systemic discrimination and in October 1996 a five-year timeline for the implementation of this was suggested. As we can see from the article about Julien in 2006 this does not seem to have progressed.

So how does the Canadian government fare in the consultation debate? Paul Howard (2004) suggests not very well. He discusses the process an Education Commission undertook when asking for submissions on a report about inclusion in school. The report was released for consultation in July 2002 with submissions due by the beginning of October. Given that most teachers, principals and school board personnel were on summer vacation from July till mid September he felt it was an unusual time to undertake consultation about education. His report states that most educators, if they heard about it all, found they only had a few weeks to digest the paper consider the response and prepare a submission. Howard (2004) says that after receiving the written submissions the commission conducted six days of public consultation hearings, however delegates that appeared before the panel were invited to do so by the commission.

Julia Abelson et al. (2004) undertook research on consumers' experiences of public participation processes. They state that health policy decision-makers are grappling with increasingly complex and ethically controversial decisions at a time when consumers are demanding more involvement in these decision processes – processes they perceive to be ensuring public accountability. In contrast to Howard (2004),

Abelson et al. (2004) believe that the government is making an effort to address consumer consultation. Policy decision-makers have established new mechanisms for consumers to contribute to public policy decisions. The Royal Commission on the Future of Health Care in Canada recommended establishing a National Health Council like its UK counterpart. At other levels of the health system efforts continue to involve consumers more effectively in priority setting and resource allocation decisions both regionally and centrally. They do however feel that the checkered history of previous efforts to involve consumers in health system decision-making has affected public confidence. They feel that trust in representative democracy and all political institutions has declined contributing to a frustrated public dissatisfied with the status quo yet unable to find meaningful ways to participate.

Abelson et al. (2004) say that in the Canadian health system, like many other publicly funded health systems, there are numerous ways in which consumers can participate outside the electoral process. They believe that knowledge of what consumers can expect from the public involvement experiences has improved over the past decade, although it remains fairly superficial. Experimentation with public involvement methods in health planning, priority setting and resource allocation processes, has generated knowledge about the health care decision-making roles that patients and consumers are willing to accept for themselves. Abelson et al. (2004) report that public opinion surveys have documented that consumers want to be involved in major public policy decisions, in health in particular, and would feel more confident in government decision-making that regularly sought informed input for average consumers (Abelson et al., 2004).

In Abelson et al's 2004 report, research participants described their frustration with consultations that were used to mask hidden agendas. Especially when decision-makers are looking for public support for predetermined outcomes and where challenging stakeholders were excluded. These negative experiences lead one consumer to suggest to Abelson et al that poor consultation practices are partly responsible for broader societal trends of declining citizen participation, a more disengaged citizenry and an apathetic society. Consumers said in their report that to minimise disappointment public participants had become more selective about their involvement. If the topic and purpose of the consultation is clearly stated then consumers can determine their level of participation, (anon, 2006).

In Abelson et al's research participants identified the importance of public consultations as a valuable tool in a democratic society. Participants stated that public consultation is here to stay so the thing is to make it better. Participants identified one particular area that needed action was to establish or re-establish trust between consumers and decision makers. One participant said,

> Whether there is a public consultation or not, I expect my elected official to be out there talking to people including me about what is going on. Public consultations are not a substitute for my elected official doing whatever they need to do or are paid to do. Their job is to find out what people want (Abelson et al., 2004).

Abelson et al. (2004) believe that any suggestion that simply establishing another mechanism for giving consumers a say without paying attention to the purpose and process has a good chance of failing to establish or re-establish trust between consumers and the decision-makers. They feel hope lies in the emerging evidence that the cycle of enthusiasm, disappointment, cynicism and apathy that has characterised public consultations over the last two decades may be coming full circle again but only under the right conditions (Abelson et al., 2004).

3.4 United Kingdom

Anderson et al. (2002) state that it is no longer an option but a duty of the National Health Service (NHS) to involve consumers in the planning and development of services. Their study, which explored the development of public involvement work in six primary care organisations, found that very little investment was made either in the front-end involvement work or the internal process of change. They also found that greater resources were needed. They believe that the development of a public involvement strategy is critical but you also need corporate commitment to public involvement. Their research found that out of the six primary care organisations studied only three produced public involvement strategies and these strategies were rarely referred to after their approval. Two of the strategies did little more than describe the existing practice. They believe that the failure to use strategies as critical documents for

ongoing practice reflects the general problems of planning in the health service and the particular difficulties of developing public involvement with minimal resources.

Anderson et al. (2002), when talking with the primary care organisations that did not have a strategy, found that they had little regret about this. Another key issue Anderson et al. (2002) found was that public involvement work rarely started from the user or consumer perspective. They state that wherever it starts, it always ends up as a negotiation between institutional and consumer voices. They felt that new government guidance on public involvement would have idiosyncratic, marginal affects until the NHS plan forced everyone to consider the future of their practice.

J Graham et al. (2001) state that people are keen to be heard however, competing demands and limited resources make it difficult for community groups to the allocate scarce resources to consultation. They believe that funding bodies need to allocate resources themselves to consumer consultation if it is to become the rule rather than the exception.

Nilsen et al. (2006) looked at two studies about consumer involvement in the development of patient information material. They found that the leaflet that was developed using consumer consultation included more information, scored better in a readability test, had improved layout and illustrations simpler language and included more detailed practical information than the leaflet developed by health professionals alone. They believe that these two studies present moderate quality evidence that consumer consultation prior to developing patient information material results in material that is more relevant readable and understandable to consumers.

When Nilsen et al. (2006) looked into studies about consumer involvement in developing health care policy and research they found only one study of consumers collaborating in an ongoing working relationship and no studies of consumer control. They found no studies of consumer involvement in decision-making. Consumers only collected or provided data to aid decision-making. One of the points participants made in their study was that consumer involvement slows the process down and makes it costlier.

Anita Franklin and Patricia Sloper conducted research in 2007 into children participating in decision-making. They found that a survey of social services departments in England suggested that involving disabled children was still patchy and required further development. In their study professionals showed some confusion about what participation should or could mean for disabled children particularly those with communication and or learning impairments. There were concerns over children's competence understanding and abilities to participate coupled with concerns about the interpretation of children's views. They found that some parents also expressed concerns about how the child could be involved and/or questioned the ability of the social worker to get the child's view. Many parents reflected, to Franklin and Sloper (2007), that they had underestimated their child and the methods being adopted.

Franklin and Sloper (2007) also found that much of the participation activity was not embedded in the culture of the organisations concerned and appeared to be carried out in isolation from other activities. They found that the measuring and documentation of the outcomes of participation activity is still an underdeveloped area.

In 1998 *Modernising Social Services* was published, in 2000 the *NHS Plan* was introduced and in 2001 *Valuing People* and *Involving Patients and the Public in Health Care* were published all describing reforms to the way health and social care organisations operate. Fundamental to these reforms was a commitment to give people the power to make decisions about the planning, delivery and monitoring of their services (Bonser et al., 2003)

Public and Patient Forums were set up in 2005 for each NHS Trust to try and improve the level of consultation and watch over the conduct of individual trusts (Carvel, 2006). John Carvel (2006) goes on to explain how Local Involvement Networks (LINKs) were set up a year later to replace these forums. He says that NHS Trusts largely ignored what the local people said in the forums and that the new LINKs are now attached to geographical areas rather than individual Trusts and so look after all the concerns of consumers throughout each geographical area. David Brindle (2006) says that the forums were short lived and little loved and believes LINKs are intended to provide more flexible ways for communities to engage with health and social care organisations.

Carvel (2006) says that while Ministers speak a lot about turning the NHS into a patient led service, they have been reluctant so far to say how patients' representatives can be given a stronger influence on key decisions. In his research he quoted Rose Winterton, UK Health Minister, saying she wanted consumers to become active partners however, Ms Winterton at the same time confirmed the abolition of the Commission for Patient and Public Involvement in Health set up less than three years ago after the government abolished Community Health Councils.

Over the last three years the UK Government put in place Community Health Councils and then replaced them with the Commission for Patient and Public Involvement in Health, and set up Public and Patient Forums that have now been replaced by LINKs. Carvel (2006) reports that work is underway to explore ways of creating an even stronger voice at a national level and hopes the government can find a solution it can stick with soon.

Involve commissioned a report in 2005 on the impact of consumer input in 11 research projects, known collectively as the London Primary Care Studies Programme (PC 11). They reported that the majority of the respondents, 89%, said they believed in the need for consumer involvement from the beginning of their project with 28% stating that consumer involvement should have taken place at an earlier stage in the project. A large majority of respondents, 82%, agreed or strongly agreed that consumer involvement in the project had been useful, with the same percentage of respondents saying they believed that their involvement in the project had or would have a positive effect on the outcome. Fourty-six percent of respondents agreed that the project had changed their views about consumer involvement and 51% planned to use consumers in future research.

Involve reported that some of the participants felt remote from senior researchers and clinicians, and did not always feel able to contribute or understand the jargon used. However, others described experiencing empowerment, mutual respect, supportive environments, good communication, appropriate language and good resourcing. Consumers reported that they influenced the research by effecting changes to research questions, suggesting new or revised questionnaires, changing interview designs and suggesting new ways of collecting data, (Involve, 2005).

Brindle (2006) profiles a report by Demos on consumer participation. This report argues that trying to boost public participation in conventional ways may be a lost cause. Inevitably, it contends, you end up engaging only the usual suspects and securing little positive benefit in terms of building social capital. Demos state it is far better to accept a realistic target of mobilising just one percent of the population but to make sure that it is the best one percent and to think innovatively about its links into the broader community.

Disability Now (May 2007) does not believe that there is real commitment by government to participation. The article, *Forum Not Run by Disabled People,* reports that a national forum that was set up to give people with learning disabilities a say in government policy, was not lead by disabled people. Regional branches were controlled by people without learning difficulties, forum members with learning difficulties were carrying out mainly non-paying roles, while coordinators and support workers without a learning difficulty were paid, (Disability Now, May 2007).

The National Consumer Council found in their report *Putting up with second best* (2002) that while there's huge interest in encouraging consumers to become involved, without the right mechanisms for involvement and representation and proper information and feedback, people are unlikely to get involved. It reported that people find it hard to see how their getting involved will influence issues and believe it will make no difference as there is mistrust and a belief that public consultation is just an exercise. The Council says that consumers are often fatalistic and believe they will be made to feel small or stupid. Others consumers expressed a view that public sector organisations consult consumers because they have to rather than because they want to.

The Council also identified that consumers have very limited perception of representation and relatively low awareness of regulatory bodies. In their report, *Visible, accountable and achieving?* (2002), they found that participants found it hard to identify with the abstract concept of representation. What knowledge of representation they did have was gathered from the popular media, local consumer advice centers and consumer publications.

3.5 United States

Fifty-four million Americans have a physical and/or mental impairment that substantially limits their daily activities, (Office on Disability, 2005). The Office on Disability reports that from the 1970's up to the present, advocacy by disabled persons has become increasingly visible nationally. They believe that the emergence of the disability rights and independent living movements has been pivotal in the development of state and federal disability policy leading up to the enactment of the Americans with Disabilities Act (ADA) in 1990. Disability advocacy has also been directed towards promoting the full participation of disabled people in community life. The ADA reaches farther than previous laws by applying to private entities not linked to federal funds and to places of public accommodation, (Office on Disability, 2005).

The ADA (1990) expanded a number of sections of the Rehabilitation Act 1973, especially in the area of communications. It stated that all government communications must be accessible, that telephone companies must provide telecommunications relay services that allow individuals with hearing impairments to communicate using a TTY or other non-voice device and that all television public service announcements include closed captioning, (Office on Disability, ADA, 2005).

In an address to a White House Employment Panel on Disability and Cultural Diversity in 1999, Federal Communication Commission Chairman William Kennard was asked what the cost to the economy would be of making telecommunications accessible. This was in light of a new ruling under Section 225 of the Communications Act requiring manufacturers and service providers to ensure telecommunications products and services are accessible to disabled people. He answered,

> If you want to talk about cost, think about the cost to our economy if we don't take steps to make sure that all members of our society can access telecommunications – the costs to our productivity, the wasted potential, the loss to our society. The cost of not making telecommunications accessible that is what we cannot afford.
>
> (FCC News, July 1999).

The ADA had a critical role in removing physical and attitudinal barriers faced by disabled people in America. In 2001 President Bush introduced the *New Freedom Initiative* to help ensure the remaining barriers to the full integration of people with disabilities into everyday American life, were broken down. The New Freedom *Initiative* was to help ensure that all Americans had the opportunity to "learn and develop skills, engage in productive work, make choices about their daily lives and participate fully in community life", (Office on Disability New Freedom Initiative, 2005).

In 2002 *Delivering on the Promise*, a cross-department report, heightened the governments' determination to move the *New Freedom Initiative* from promise to reality. This report identified a number of solutions to remove the barriers that exist. In 2002 the Office on Disability was established and charged with the responsibility to lead the New Freedom Initiative. Part of their role was to ensure disabled people had a voice, (Office on Disability New Freedom Initiative, 2005). The most recent record of how the Office on Disability is meeting the objectives of the *New Freedom Initiative*, that could be found, was for 2004, titled *Record of Accomplishment*. Whilst the Office on Disability commented on a number of initiatives that had been put in place, there was only one reference to actually engaging with disabled people and that was in relation to Medicare/Medicaid organisations receiving feedback, (Office on Disability Record of Accomplishment, 2004). There seemed to be a lot of planning and development of guidelines and other initiatives but no mention of how disabled people could or did have input into developing them.

Mari-Lynn Drainoni et al. (2006) ran a number of focus groups with disabled people about the barriers they face accessing health care. Their study highlighted a number of issues that still exist despite the Rehabilitation Act, the ADA and the *New Freedom Initiative*. Individuals with speech or hearing impairments described communication problems when they attempted to contact providers' offices by telephone. Drainoni et al (2006). found there was a lack of TTY machines or staff properly trained to use them in health-care settings and staff were often rude or impatient. Deaf people had difficulty obtaining American Sign Language interpreters for medical visits on short notice and providers were sometimes unwilling to write out their findings or, if they did, used medical terminology that the patients did not understand.

Their study found that there was insufficient knowledge about disabilities among health care staff and misconceptions about disabled people. They found that staff often had preconceived ideas about people's disabilities, and sometimes showed insensitivity and lack of respect. Disabled people reported they felt they were not taken seriously and those with psychiatric disabilities were reluctant to reveal their diagnoses to health-care providers for fear of stigmatisation. They felt some providers failed to take their input seriously. Some specific comments included,

> They write us off as difficult.
> I was treated like a child.
> They acted like everything that happened to me was my fault.

(Drainoni et al., 2006).

All of this data indicates that despite gains since the passage of the ADA, disabled people continue to face significant barriers to health-care access.

Many of the requirements of the ADA, Communication Act and Rehabilitation Act still seem far from being achieved. A fact sheet in June 2007 stated that, "As of January 1, 2006 all "new" English language programming defined as analog programming first published or exhibited on or after January 1, 1998 and digital programming first aired on or after July 1, 2002, must be captioned, with some exceptions". These exemptions include programmes that are primarily textual, those shown between 2am and 6am, public service announcements less than 10 minutes that are not government funded, programmes that were first shown prior to January 1 1998 and where to add captions would cause undue burden (such as different languages, small local television stations). So 16 years on from the ADA saying all communications must be accessible and they are still working to achieve this, (FCC Consumer Advisory).

Chapter Four – Findings

There is a mix in the data available to analyse. The UK for instance provided far greater amount of data detailing the effectiveness (or not) of government attempting to legislate consumer engagement into the culture of government organisations, than other countries. In the US it was more difficult to find data actually detailing any information on progress towards increasing consumer participation. There were also some differences in the legislation that each country had put in place with disability specific Acts of Parliament in the UK, US and Australia and disability specific strategies in NZ, Australia and the UK. Canada seems to have had some difficulty getting legislation off the ground with the five year planned implementation of a Canadians with Disabilities Act being announced in 1996 and in 2007 nothing yet in place. Canada also seems to have some difficulty with achieving collaboration. Their *In Unison: A Canadian Approach to Disability* did not include Quebec, and Ontario has its own Ontario's with Disabilities Act separate from other parts of Canada.

But one of the major achievements in the disability arena has been the UN General Assembly adoption of the UN Convention the Rights of Disabled People, the first legislation recognising disability as a human rights issue. It opened for ratification in March 2007 and had the fact that it had the highest number of signatories of any UN convention on its opening day indicates the increasing importance countries are placing on ensuring disabled people are full citizens, (Convention on the Rights of Persons with Disabilities, May 2007).

There seems to be much interest and belief, on paper, that consultation is a positive thing and can only lead to an improved health and social care service; however the research seems to suggest that some of it is just that – on paper only. The actual attitudes towards consumer consultation of the people who will have to carry it out seems at times at odds with what government says it wants to do. When questioned, Bastion (1996) discovered that many professionals actually believed in consumer consultation only in specific cases and felt that at times it diminished the credibility of decisions in the eyes of other professionals.

Osgood's Theories on Message Reception (Osgood, 1963) say that we have associations and meanings attached to certain words, ideas or concepts and as such when we come into contact with these ideas/words/concepts we will behave in a certain way because of these associations. Consumer consultation is a perfect example. Different people have different understandings of consultation – some see it as informing people, some see it as discussing plans and yet others see it as a fully participative process between two or more people/groups with a common agenda. Depending on the meaning you have attached to it will depend on how you approach the process, how you behave in the process and your level of satisfaction.

Heider's Attribution Theories (as cited in Littlejohn, 2002, p 120) also sit well within this frame of consumer consultation. He says that people behave a certain way because of the situation they are placed in, and/or their ability to influence things personally. If the environment that the consultation is being conducted in is 'hostile' then people may behave differently than they would otherwise. This would be particularly relevant for disabled people. A 'hostile' environment for them might be one where the physical environment is not accessible, where the information isn't in a format they can use, where they have had to travel a long distance or are outside their comfort zone. The use of jargon and acronyms, which are well entrenched in bureaucracy, is another way of making an environment 'hostile'.

Information Integration Theory (Fishbein, 1975) attempts to explain how people accumulate information about people, objects and situations and form attitudes. These attitudes affect how they behave and while they can change, it takes a positive, believable experience to turn a negative attitude into a positive one. The study by Involve (2005) showed that 89% of respondents (from primary care trusts) believed in the need for participation with 46% changing their views on the value of participation. This positive experience will influence how they engage with consumer participation in the future.

All countries identified much of the same thinking around the benefits of consultation and there were also many similarities with what people perceived to be the difficulties in actually undertaking consultation. Two of the largest hurdles seem to be attitude towards the value of consumer input and genuineness. Many consultation practices

that were explored appear to be a little like window dressing – done only when there was already a well formulated action plan and the aim was to get confirmation of it. According to Nilsen et al. (2006), barriers can be resolved with time, commitment and the right attitude. They say that most health professionals are hierarchally socialised and organised to view themselves as authorities. They believe that consumers may not find it meaningful to function as consumer representatives because their opportunities for input and influence are minimised.

The UK Department of Health in their 2005 report, *Involving Patients and Carers,* identified a number of concerns that patients and staff might encounter when thinking about patient involvement in planning and decision-making:

Patients might be anxious that	Staff might be anxious that
• Their views will not be taken seriously • They will look foolish • They won't understand what's being talked about	• Their work will be criticised • There will be unrealistic demands to change services • Their role and authority might be undermined

Fig 9. Adapted from Fletcher G and Bradburn J, Voices in Action Resource Book, 2001.

Trevor Gay (2003) describes a number of misconceptions surrounding consumer involvement that can be used at times to justify not engaging with consumers.

1. They don't understand – Gay believes by giving them the right information and time to digest it then they will be able to understand
2. Consumers are not representative – correct and why should they be? Gay states that consumers generally do not profess to be or ask to be representative. They can only respond from personal experience
3. Hard to reach groups – Gay believes there is no such thing. People are easy to reach you just have to find them. You should go to where people go
4. Consumers talk about wants, we know what they need – Gay believes that when consumers are told honestly the options open to them they accept limitations on the service but only once they have been told the truth
5. It will create demands we can't cope with – Gay again believes that consumers are adult sensible people who act rationally and reasonably most of the time

6. It will cost too much – Gay says people use lack of money as a good reason not to do things, however this is public money and should be used for public good

7. Staff don't have time to do all this is well – Gay states that staff already do it all the time, all we need to do is make sure that the organisations' culture is about partnership with consumers not a master/servant, control/command relationship

8. Consumers are not really interested in all this anyway – Gay says this is incorrect.

(Trevor Gay, 2003)

Anderson et al. (2002) believes that undertaking consumer consultation because it has to be done is exactly the sort of practice that infuriates people who are invited to participate. They say ticking the public involvement box and doing no more is a waste of everyone's time. They found that working in partnership is often treated with suspicion by many professionals who can identify the costs of partnership but not the benefits and that public involvement work often suffers from a lack of clarity about its aims.

Anderson et al. (2002) also describe how easy it is for public involvement methods to gain a life of their own and be continued with no agreement about what they are trying to achieve. They identified that there are likely to be many potential stakeholders with different degrees of power, influence and commitment and that often authorities take great care not to commit themselves to taking action on the results of the consultations. This is usually said to be because the views of consumers must be balanced with other views. Anderson et al. (2002) identified some practical difficulties such as negotiating across diverse interests and getting the balance right between discussion and implementation. Too little action and disillusion and frustration soon set in.

Anderson et al. (2002) say the choice about whom to engage in public involvement can be difficult to make with the diversity of local populations. Often strong voices end up being heard more as they are easier to engage with. Targeting marginalised groups takes more time and innovative initiatives.

Wilcox (1994) tells us that participation doesn't just happen, it needs to be initiated and the initiator is in a strong position to decide how much or how little control to allow

others. Participation involves a power balance. Who holds the balance will depend on who has information, money, confidence and skills, (Wilcox, 1994).

Coney (2004), suggests that consumers view the health sector as powerful and difficult to change and that there is some skepticism about participation based on previous experiences. In the UK, audits have found that while there is a great deal of consultation activity, little of this has entered the corporate bloodstream. There is a scarcity of evidence about the participation of consumers in decision-making and policy setting, especially at a high level, (UK Audit Commission, 2003). It seems that very often, participation occurs at some distance from the important decision-making processes and structures, at the periphery of the system. Coney (2004) has found that here is little evidence so far, that consumer participation activities lead to a redistribution of power or resources.

As we have mentioned participation requires partnership, which in turn requires power sharing however, those in the system often find it hard to give up control. Teicher, Hughes and Dow (2002) believe that so far participation has largely been occurring on terms set by non-consumers whereas it should be a partnership, including power sharing, at every stage. The UK Audit Commission (2003) agreed and went a step further saying that wherever possible organisations should be prepared to hand over control to service users and that consultation and involvement should be lead by service users. They felt a key feature for success was the willingness to hand over this control to the service users or communities involved.

Teicher, Hughes & Dow (2002) agree that there appears to be little evidence from the literature that would suggest power sharing in its truest form. They felt that some of this may stem from the fact that in the public sector outcomes are harder to measure, there is less freedom to be arbitrary, decisions need to be firmly based in law, there is more scrutiny from the press and public and there is the pervasive influence of politics and accountability to political appointees. They believe the biggest difficulty in dealing with a public sector environment has been the ability to measure outcomes or even outputs in meaningful ways, and this places real restrictions on the capacity to apply concepts of quality derived from the private sector or from consumers.

Most of literature so far (Anderson et al., 2002; UK Department of Health, 2006; Franklin & Sloper, 2007; Abelson et al., 2004) assumes that input from consumers in the planning and delivery of health care can lead to more accessible and acceptable health services and improve health and quality of life. However, Nilsen et al. (2006) tell us that there is a lack of research that reliably investigates whether consumer involvement achieves these intentions and, if so, which methods of consumer involvement are most effective. While there are plenty of guidelines on how to involve consumers in decision-making and planning (NHS Modernisation Agency, 2005; In Unison, 1998), and everyone seems to know what and how it should be done there is limited evidence that governments are actually achieving it.

Often organisations think, "we are required to consult with consumers, so lets go talk to some people", and off they go, round up some consumers and ask them what they think. However, consultation that arises from a statutory requirement or management directive alone will often fail to deliver the goods, (Audit Commission, 2003).

The UK Audit Commission (2003) and the UK Department of Health (2006) among others agree that developing a strategy is critical before organisations start down the path of consumer consultation. They believe this will help them to define exactly what the purpose of the consultation is, what they want to achieve, help them identify the relevant stakeholders and assess what level of engagement to undertake. This strategy could be for a particular project/decision or as an annual plan of how to increase participation across the board. However, there is limited evidence from the literature that many organisations do this at all and in fact Anderson et al. (2002) identified that not only did few organisations have a strategy, those that did have one didn't use it, and those that didn't have one weren't really concerned.

In the UK Audit Commission's 2003 report on government organisations' consumer consultation work, none of the bodies had an overall vision strategy plan for consultation. They state that an organisations commitment to involving service users can be shown by the extent to which consultation and involvement is supported by cross-organisation structures. They believe it needs cooperation and coordination across a range of departments and levels and that senior managers should ensure that public involvement is considered in funding, planning and training. The report identified

that cross-organisational planning should take account of the need for ongoing community and consumer involvement feeding into long-term planning as well as short-term or one-off research or consultation on specific issues and services.

A number of the other studies (Anderson et al., 2002; UK Audit Commission, 2003; Nilsen et al., 2006) agreed that support and co-operation from everyone taking part was a key element in developing a successful initiative. They felt that support was necessary at all levels, from frontline staff to senior management and from the full range of agencies involved. The concept of consumer participation needs to be part of an organisations culture. However, the UK Audit Commission (2003) report found that participation seemed to be a somewhat ad hoc addition and often done by a particular section or group within an organisation because their manager or someone within the section thought it was a good idea and was motivated to start the process. Less often did there seem to be buy-in across the whole organisation with all sections co-operating and working together on an overall strategy, (UK Audit Commission, 2003).

The UK Audit Commission (2003) also found that organisations needed to be careful that they did not create 'professional consultees'. They say the aim for choosing participants for consultation are that they are representative of the stakeholder community and do not unintentionally exclude parts of that community. The UK audit identified that some organisations find it difficult to achieve a fully representative mix. Many organisations achieved wider involvement of the community by showing specific attention to the needs of those people that they wanted to engage for example they subsidised bus travel for disabled service users and identified the access and support needs of individual group members. The UK Audit Commission (2003) found that the initial establishment of a consultation approach could lead to a growing network of groups and structures but that membership of long-term groups needed regular review to help new people get involved.

It is also vital that consultation processes are able to grow and develop according to changing needs and not remain static, (UK Audit Commission, 2003). Lessons learned should be incorporated into new approaches with regular evaluations of whether the involvement process is meeting its objectives and what is being achieved as a result. A priority for people is that they can see their contributions having an influence on

decisions, policy making and service development, (Audit Commission, 2003). They value seeing concrete decisions and actions rising from their input, including evidence of real change in the long-term, (Audit Commission, 2003). The involvement of service users in the PC 11 study (Involve, 2005) is one of the few documented cases of consumers' input actually having some influence, when a number of the approaches, information presentation and gathering was amended to reflect their input. Disability Services at the NZ Ministry of Health is another example where consumer input has resulted in changes to some processes and the initiation of some projects to meet the identified needs.

One of the major improvements to enabling disabled people to become involved is through information and communication technologies and the internet. Universal design is becoming an increasingly popular phrase as companies start recognising the huge potential of the estimated 600 million disabled people currently missing out, (Kahn, 2004). Screen Readers, Voice Recognition Software, Braille keyboards and touch screens are just some of the technologies available. However if they are not designed with disabled people, and other disadvantaged groups, in mind then they are neglecting a large section of the community, (Gould, 2007).

The use of the internet especially in developed countries is opening up a world of information to everyone. However many organisations fail to take even a few simple steps to ensure that disabled people, among others, can access this information, (US Department of Justice, 2001). The use of certain design features and lack of text descriptions of photos/graphics makes using the internet difficult for many people. Simply providing information in HTML or text format instead of all as pdf documents can make a huge difference, (US Department of Justice, 2001). Taking into account once again the estimated 600 million disabled people in the world who, like everyone else, would shop on-line, communicate with others and subscribe to many services if only they were accessible, and it seems that yet another market is ripe for expansion.

4.1 So why bother consulting?

Coney (2004) says that there are a number of rationales for consumer participation such as citizen participation rights, empowerment of consumers, enhancing accountability and legitimising decisions made by managers and health professionals. She believes that involving consumers will lead to more responsive and acceptable services and improve the quality of health care.

The NZ Health Strategy (2000) states that consumer consultation contributes to the development of good public policy and helps organisations to gain the full picture, understand and identify different communities' needs and priorities. It also helps ensure organisations are accountable, acceptable and that consumers' rights are upheld. Consumer consultation helps ensure provider, community and consumer input is valued, provides opportunities for communities to participate and enhances decision-making. It helps to build positive relationships, consensus and better more sustainable decisions.

Consultation develops a sense of partnership in the decisions that are made, leads to collaboration and gives a shared understanding, (New Zealand Health Strategy, 2000).

Nilsen et al. (2006) says the potential benefits of consumer involvement in health care include policy, research, practice and information that includes consumers' ideas and/or addresses their concerns. They say consumer participation can be viewed as a goal in itself by encouraging public accountability and transparency. Consumers may offer different and complementary perspectives to those of professionals, they may also not have the same conflicts of interest and loyalties as professionals, (Nilsen et al., 2006).

The UK Department of Health (Keys to partnership, 2002) thinks we should be listening and learning about what disabled people and their families want and need. That means that people who use services and their families are at the centre of any decisions that are made about their lives and about the help they need to live the way they want to. This can only be achieved if people work together and consumers and organisations work in partnership.

The UK Department of Health identified in their report, *Involving patients and carers* (2005), that there is a strong and widely held view that involving patients in decisions about health care at both personal and strategic levels is fundamentally important to the improvement of health and social care services as well as being a basic right. The report identified that the potential benefits are better quality services, policy and planning decisions that a more patient focused, improved communications and greater ownership of the local health services.

The report *Public Involvement in Health and Social Care Organisations* (2003) by the National Health Service, UK, agrees and adds that working in genuine partnership can improve outcomes of care for the individual and the population, help address health inequalities, and allow a better understanding of why and how services need to change and develop.
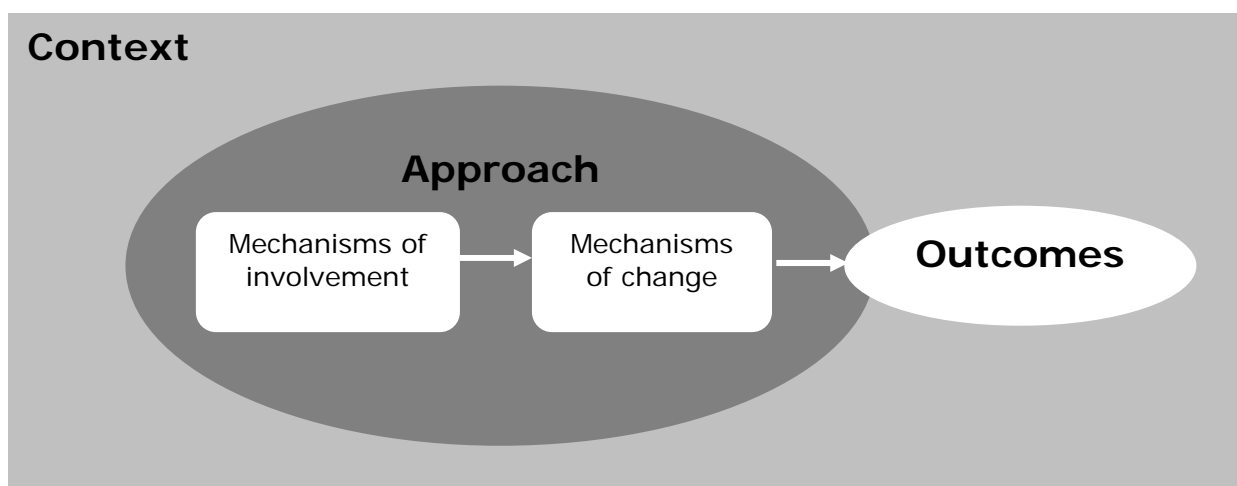

Fig 10. Anderson et al., 2002.

Anderson et al. (2002) state that policy is rarely a direct driver of consultation. People are rarely persuaded solely by the business case for public involvement, they are more likely to be persuaded by their experience of public involvement in action. The context or reason for consultation is overarching but it is the approach and the outcomes that are achieved through consultation that will influence people's willingness to engage in consultation. Commitment to consultation does not resolve the tricky question of what to do in practice. Anderson et al. (2002) suggest that as well as what others have already identified, consumer consultation can also enable local people to have a voice and some control, help change the culture of public service organisations and inform

and educate. It can improve relationships and increase the capacity of community organisations to engage with and influence statutory bodies.

For consumers effective consultation can mean they get better outcomes of treatment and care, an enhanced sense of self-esteem and capacity to control their own lives, a more satisfying experience of using health services, more accessible, sensitive and responsive services and improved health, (Anderson et al., 2002).

For the community consultation can help bring about a reduction in health inequalities, more healthy environmental, social and economic policies and improved health. It can also improve social cohesion, encourage healthy democracy and provide a health service better able to meet the needs of its consumers, (Anderson et al., 2002).

When asked why they get involved patients say,

> "I believe I can make a difference"
> "Feeling part of a movement of change"
> "Valuing and using our own experiences to bring about improvements"
>
> (NHS Modernisation Agency 2005).

Chapter Five – Conclusion

Disabled People are often excluded unintentionally from the mainstream of society. Despite some progress in terms of legislation over the past decade, this has not been systematically addressed in society. Change in the perception and concepts of disability will involve both changes in values and increased understanding at all levels of society, (UN Overview of International Frameworks, 2007). One of the dominant features of legal thinking in the twentieth century has been recognition of law as a tool of social change. Legislation represents one of the most powerful vehicles of change, progress and development in society. Legislation at country level is fundamental however, international norms are used for setting common standards for disability legislation, (UN Overview of International Frameworks, 2007).

The acceptance of the UN Convention on the Rights of Disabled people has made governments think about disabled people and how they can build an inclusive society for all their consumers. Consulting with consumers is one of the fundamental ways of finding out what people want.

> Trust me I am a patient – I use the services, I understand my illness I have views on how you could make services better for me.
>
> (Harry Clayton as quoted in Gay, 2003)

A number of communication theorists have developed frameworks to explain why people behave and communicate the way they do such as Osgood's Theories on Message Reception (Osgood, 1963) and Heider's Attribution Theory (as cited in Littlejohn, 2002, p 120). We also only have to look at the difficulty of firstly deciding we want to consult, then deciding who to consult, why and how and then actually doing it.

People have different ideas of what consultation means and depending on their frame of reference, the whole concept of consultation can take many forms. Consultation is about seeking input from the people who are or will be affected by the decisions that are being made. There are many perceived difficulties with undertaking consultation such as time it takes, usefulness of information received, validity of the decisions, willingness

to develop the relationship. So why do we consult? Increasingly governments are legislating for consultation, and increasingly consumers are advocating for a say in the planning and development of services especially in the health and social care sectors. However, without all stakeholders seeing a value in consultation processes it is a difficult task to undertake successfully.

Bastion (1996) tells us that the rationales for seeking community participation often fall into three categories to improve services and decisions, to gain legitimisation and/or community compliance or to bring about social change with the redistribution of power or resources

Anderson et al. (2002) believe public involvement is driven by values. These values encompass both the process of involvement – dialogue, partnership, communication – and its broader goals. Participation is an active process where participants should at least have the potential for influence. It implies partnership and sharing of decision-making power. Commitment to ensuring that consumers views have an influential role requires considerable effort, however, and involving consumers can ensure genuine agreement.

Anderson et al. (2002) tell us that, most people agree that outcomes are what really matter, and that although there are many examples of consumer consultation work delivering little, the potential is enormous. In effective consumer consultation everyone stands to gain.

This literature review showed that while governments around the world are starting to embrace the concept of consumer consultation and legislating about it there is still a long way to go before the organisations themselves change their culture and engage in meaningful consultation with consumers. Out of the countries reviewed the UK seems to be the furthest along the path to effective consultation but even they had more examples of it not working than of it working. There was fairly universal agreement on how to effectively engage consumers in theory, there was little evidence of it being put into practice.

This project also highlighted the different reporting requirements that different countries have. It was more difficult to find information on what was being undertaken in the US except on technology under Section 508 of the Rehabilitation Act. Whereas, it was far easier to find information from the annual reports on implementing disability policy in NZ, UK and Australia.

Information and communication technologies seem to be one area where standards on accessibility are trying to keep up with rapid advances in development. Most governments have basic standards on the accessibility of websites and are providing access to an increasing range of technologies designed to open up the system. Increasingly organisations and governments are recognising the potential market if they design for inclusion not exclusion. In order to get it right and address the needs of disabled people, designers need to find out what these needs are. The only way they can do this is through consultation. If they don't consult and don't produce usable solutions then disabled people won't buy it and the potential market is lost. If they leave it too late in the process then any changes they want to make will become more difficult and costly and once again if it's unusable then it won't be bought.

Consultation is an important part of designing, delivering and managing effective health and social services. Governments expect it to happen, consumers want it to happen, so organisations need to find a way to make the vision a reality. Currently the methods put in place to enable consumer consultation usually involve so little participation and at such a late stage in the process that it would be hard to show any effect of that consultation.

There are many different ways of engaging consumers and finding the right way for each organisation takes planning, commitment, time and energy. Dismissing the importance and feasibility of consumer participation just because there is not one perfect that way of doing it, is unwise at best and potentially disastrous.

Whatever method/approach is chosen, involvement needs to be a continual process not a one off event. It has to be backed up with objective, trust worthy, comprehensive information to help consumers contribute. There needs to be clear feedback on the outcome of their input and any impact it has had on decision-making. To make

consumer involvement effective, consumers need to feel confident there is real value in getting involved. Consumers need to feel that their concerns are being addressed, and that there is a meaningful way they can get involved and make a difference.

Public views do not sit neatly within institutional boundaries. The process of shared learning from public involvement initiatives helps to ensure that public voices reach the places where change is possible. Achievable in theory, remarkably difficult in practice. Collaborative practice in public involvement is still relatively uncommon which means we don't maximise the value of what already exists.

Wherever and whatever countries are doing in the disability field, what does seem to be clear is that consumer participation is here to stay and the sooner governments get to grips with the meaning of participation the sooner it will be embedded into their culture.

Chapter Six – Recommendations for Disability Services of the New Zealand Ministry of Health

Attitude towards consumer consultation is critical. For it to work effectively, consumer consultation and participation needs to be an integral part of an organisations culture. It needs to be embedded in that culture so that it becomes the norm not something that is tacked on in the middle or at the end. In order to get buy-in to the concept and practice of consumer consultation it needs to be an expected standard but also needs to be seen to add value to the organisation and people's work as a whole.

1. Identify what Disability Services **aims and objectives** are for undertaking consumer consultation. What do they want to achieve and why.

2. **Evaluate existing practice.** Look at what Disability Services currently does and evaluate that against the desired outcomes of consultation. What is working what is not and how can this be changed?

3. **Facilitate a discussion** with staff including the Senior Management Team on their understanding of what consultation and participation means including any constraints and barriers they identify. Look at ways you could minimise the impact of those constraints and eliminate the barriers. Look at the type of situations when you need to consult and discuss which level of participation is appropriate for those situations.

4. Develop an overall **Consumer Participation Plan** as part of a wider Stakeholder Consultation Strategy for Disability Services. This will involve a project group from within Disability Services with representatives from each team. The Senior Management Team and consumers should also be involved in this process.

5. Run **training sessions** on how to consult with consumers including provision of accessible information, language use, accessible venues and use of technology. Create a library of articles on consultation available to staff.

6. Develop consumer consultation **champions** in the workplace to encourage others to incorporate consumer consultation into their work.

7. **Incorporate consultation into documents.** Add in a consultation section to the generic communications plan template and any risk management documents. Within the Project Management Framework, add in consultation as part of the project brief and project plan templates. Incorporate a consultation section into planning and discussion documents such as Senior Management Team templates.

8. Ensure **adequate time and resources** are allocated to allow consultation to take place including the need for accessible documents, locations.

9. **Ongoing shared learning**. Feedback to colleagues on the consultation, what went well, what didn't, what could be changed.

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