THE ELEVENTH SIR JOHN QUICK BENDIGO LECTURE

Integration, Quick Smart:
Disability and Community

by
Dr Rhonda Galbally AO

Chief Executive Officer
Our Community

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ABSTRACT

*A*ll our social systems tend to work on the basis of a 'medical model' of disablement, where problems are an individual matter based on the consequences of diseases or trauma. The 'social model', in contrast, sees disablement not as an attribute of the individual but a complex collection of conditions, many of them created by the social environment. A social justice model provides the opportunity to bring people with disabilities back from the margins and to integrate their needs and rights into the mainstream on an equal footing. Our approach to disablement must be founded on the principles that:

- Everyone is of equal worth
- Everyone is entitled to respect and personal autonomy
- Everyone is entitled to have his or her basic needs met.

A policy on disablement that sought to implement these principles would involve major changes at all levels of the health system. Without such a policy, community access will be denied to the population that is in most need of it.

RIGHTS IN AUSTRALIA

This being the Quick lecture, I have to say at the outset that I have a bone to pick with Mr. Quick. He was, after all, one of the founding fathers of the Australian Constitution, and had some say in the absence from that Constitution of a Bill of Rights. Indeed, his massive tome on The Annotated Constitution of the Australian Commonwealth uses the words 'riparian rights' (which are rights to fish in rivers) several times, but the words 'human rights' not at all.

His attitude was understandable. He lived at a time when few women and almost no indigenous people had the vote, a time when Jeremy Bentham derided human rights as 'nonsense on stilts' and when conservatives looked at the British legal system and declared that all was for the best in the best of all possible worlds. The British legal system which we inherited was based on self-enforcement by an active citizenry prepared to go to court at the slightest threat to their interests, and this tended to mean 'Every man for himself and the devil take the hindmost'; and people with disabilities were very much the hindmost. Those who did work with people who were disadvantaged, poor or disabled saw their work as charity, and expected a proper gratitude from the objects of their charity.

Rights and Disability

It was not until the revolutions of the sixties – revolutions that grew out of the successes of women's liberation and Black Power that Australians with disabilities first began to think of themselves as a group that had any meaningful rights and began to press governments to embody these in legislation.

Many good laws – laws against discrimination and denial of opportunity - were enacted, and I would not like to underestimate the advances that have been made. However, Australia still does not have any tradition of human rights – rights that are prior to legislation and which can override it. Australians – and particularly Australians with disabilities – have no rights that their parliaments cannot take away tomorrow. Under Mr. Quick's Australian Constitution the only human right possessed by the citizen is to pass from one end of a public footpath to the other in single file at an even pace breathing unobtrusively through the nose - if, of course, you can walk. If you're in a wheelchair, you may well find that you can't get down from the kerb to the road, and you may well find yourself marooned on that one block for the rest of your life (and in passing let me say that I think the world would be greatly improved if every architect and every town planner was strapped into a

wheelchair, given a large cup of boiling coffee to sit in their lap, no hands, and told to find their way from one side of their work to the other without going over any nasty bumps. It would be a valuable discipline.)

Another way to look at rights is to look at the rights that the Australian legal system does privilege – the right to sue someone for your problems. Recently, for example, the parents of a child who has cerebral palsy at birth through the negligence of the hospital was awarded five million dollars in compensation to cover the extra expenses he would incur over his life. I'm sure the boy deserved the money, and I'm sure the hospital deserved to be penalised, but I'm also interested in what happens to the children who have cerebral palsy from birth without anybody being at fault and who have nobody to sue. Their needs are exactly the same, but their right to have those needs met comes up exactly five million dollars short, and nobody since the days of the Whitlam government has considered that this ought to worry us. It worries me. All people, without exception, should have the right to maximise their potential.

All our policies on people with disabilities should be built on a human rights perspective. As things are, systems at every level invariably marginalise people with disability. In order to overcome this situation, people with disabilities require enforceable rights to services, tribunals in which to assert these rights, and advocacy and support to enable them to appeal to the tribunals. To attain these systems, we must all change our views on what constitutes disability.

What is Disability?

Over the last 20 years there has been a marked shift in the understanding of disability policy issues. Much of this shift can be attributed to the rise of the disability rights movement, organized and led by persons with disabilities, which has fundamentally redefined the problem of disability from one of deficits in the individual to one of barriers in the environment. In so doing, the disability movement has identified public policy as an important environmental component in the lives of people with disabilities. However, policymakers' understanding of the disablement perspective remains underdeveloped. All our systems tend to work on the basis of a 'medical model' of disablement, where problems are an individual matter based on the consequences of diseases or trauma. The 'social model', in contrast, sees disablement not as an attribute of the individual but a complex collection of conditions, many of them created by the social environment.

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A social justice model provides the opportunity to bring people with disabilities back from the margins and to integrate their needs and rights into the mainstream on an equal footing. Our approach to disablement must be founded on the following principles -

• Everyone is of equal worth.
• Everyone is entitled to respect and personal autonomy.
• Everyone (not only those with compensable injuries) is entitled to have his or her basic needs met in the community.

Disability and Well-Being

A policy on disablement that sought to implement these principles would involve major changes at all levels of the health system. Without such a policy community access will be denied to the population that is in most need of it.

Disability's interaction with health, for example, is important, though subtle. The Ottowa Charter[1], the basis for modern health promotion worldwide, tells us that health is something more than simply not being sick. Health, in the WHO definition, is a state of complete physical, mental and social well-being. Good health is thus not limited to the body of a person. It includes the concept of a person who is autonomous and resilient and confident in his or her own capacity to cope with the trials of life and that of a citizen within a supportive and equitable community.

People with disabilities are not necessarily barred by their limitations from achieving these personal and social aims. We must recognise that people with disabilities can have lives that are full, resilient, satisfying, and healthy.

Our policy on disablement must establish a balance between the prevention of disablement and the promotion of well-being for people with disabilities through the removal of obstacles to full participation in all facets of social activity. There is a clear connection between the level of freedom and autonomy actually enjoyed by an individual and how that individual perceives his or her state of well-being.

Preventing disablement thus means preventing impairment, through medical and environmental health interventions, or public health prevention programs; overcoming limits to activity using technology, equipment, rehabilitation and other services and removing limitations to participation by elimination of environmental barriers, be they social, attitudinal or physical.

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[1]   www.euro.who.int./AboutWHO/Policy/20010827_2

Disability is not a feature of the individual; it is a feature of the environment. Integration and inclusion in the life of the community represents a human rights issue. Lack of integration itself contributes to poor health. Not only does it perpetuate negative attitudes in society towards people with disabilities, but in the individual it leads to low self-esteem, high levels of anxiety, and reduction in the rate of physical and psychological development.

Public acceptance of people with disabilities in the community will open up opportunities for participation in employment and activities and encourage practitioners in all areas to adapt their procedures to take account of special needs, and strengthen the social support networks so important to a happy and productive life.

Universality

Not only do views of what constitutes disablement differ between culture and culture, even within each culture it is not the case that there is a clear standard of healthy ability from which deviations may be measured. There is only an average against which one measures, depending on one's point of view, an average measure of health or an average measure of disablement. Everyone is limited in the activities in which they engage and the levels which they achieve. People are content if there are things they can do, without regarding themselves as 'disabled' because of the things they cannot do. People are regarded as 'disabled', and can sometimes regard themselves as 'disabled', when their range of abilities does not overlap with the statistical norm. Nonetheless, their range of choices about their lives and how they wish to live them can be and should be as wide a range of choices as everyone else. We must not allow ourselves to accept the propaganda that springs up every time integration is mooted (see, for example, the recent fuss over the closure of Kew Cottages), the propaganda that says "These people are happiest with their own kind". Their own kind is humankind.

Anyone can become disabled (or may have a disablement). Disablement is a universal human experience, not a trait that marks a group or person from another. It follows that disablement policies and services, as distinct from medical provision, should wherever feasible be centred on the consequences of activity limitation – on need, not diagnosis. Benefits from the removal of barriers for people with disabilities will not always be limited to them, but may be enjoyed by others. For example, ramped access will serve not only people using wheel chairs but also mothers using shopping trolleys.

For social purposes distinctions between people should be made on the basis of the nature of their activity limitations, not on the basis of their diagnosis, its cause, or its age of onset. Planners and policy makers should not distinguish between one population which is able and another which is not. Rather they should view the population in its integrated entirety, recognising that a significant proportion will have a diversity of activity restrictions.

Disablement is, like gender and race, a social construct with physical markers. Like gender and race, it requires different treatment in different contexts. There are times (counting votes, for example) when it is appropriate to treat a person with disability in exactly the same way as any other citizen. There are times (when voting, for example) when the goal of equal rights requires special provision - voting booths must be made accessible to people in wheelchairs, people with visual impairments must be provided with material in Braille or on tape. There are times (when considering service needs, for example) when the entrenched social effects of stigma, discrimination, and poverty must be given weight. There are times when the particular strengths of disability culture must be celebrated.

Disablement must be related to its particular contexts

Within disablement there are contexts where everybody with a similar activity limitation is faced with the same issues, whether the difficulty was caused by arthritis, amputation following road trauma, spina bifida, or a sprained ankle. There are, however, different contexts where different life experiences, cultural stereotyping, political activity, funding structures, self-images, and assigned roles are primary. Our policy must encompass disablement in all its contexts. We must design our systems so they do not impose functional limitations on people, and we must recognise and foster a disability culture developed and controlled by people with disabilities themselves based on their experience of cultural uniqueness.

Yes, 'disability' is socially constructed - a concept given meaning by a complex of political, cultural, social and medical factors - but many millions of people have built their identities around this construct, and their perceptions and experience must be respected. People with disabilities, have through centuries of struggle, earned the right to set the terms of the discussion of the universalisation of disablement. People with disabilities have made great advances towards the recognition of their rights. Policy on disablement must continue to be negotiated with the organisations created by people with disabilities.

Handicaps

There are many factors that can make life activities more difficult. Disability is one of these, but so are inequity, poverty, and discrimination. All can be experienced alone or in combination, and all can further disadvantage a disabled person, singly or cumulatively. Disablement cannot be dealt with in isolation from other societal relationships. Disablement policy must be integrated with policy directed towards the removal of disadvantage in other areas of life.

Poverty

Poverty and disadvantage among people with disabilities cannot be separated from a commitment to ensure developmental supports for all people faced with poverty and disadvantage. In addition, the higher incidence of disablement amongst the poor needs to be acknowledged. Poverty and inequity are factors that both raise the risk of acquiring or suffering from a disabling condition and increase the hardship and burden of disablement.

The vast majority of people with disabilities are poor.* Low-income men and women both have higher rates of disablement and chronic illness than people at higher income levels, men more than women. They also have more recent illness and much more reduced activity. Programs must take account of the contribution that poverty makes to the experience of disablement and must recognise this as both a health and a rights issue. Compensatory funding for special needs must be treated as an independent entitlement that does not affect general pension entitlements – for example, if it costs more to be in a wheelchair and to have to take wheelchair taxis rather than travelling by train, and of course it does, then that discrepancy should be adjusted separately for wheelchair users rather than expecting them to pay for it out of the same pension that train users get.

Issues of activity limitation among people with disabilities living in poverty need to be addressed both through disability-focused interventions and more general poverty-focused interventions.

Minority Status

People with disabilities who are members of a minority ethnic, racial or religious group suffer from the devalued status of the group as well as from the devalued status of people seen by society as disabled. The greatest impediment for people with disabilities is the

* www.ilr.cornell.edu/ped/DisabilityStatistics/statistics.cfm

absence of suitable resources, rehabilitation, workplace, accommodation and other necessary provisions for their participation in the community. However, in addition to these handicaps, major impediments to a disabled person's taking a full part in society come, as with ethnic and racial minorities, from the tissue of myths, fears and misunderstandings that society attaches to them.

Acceptance of people with disabilities should be seen as a public priority in the same way as the elimination of racial prejudice. Nevertheless, programs emphasising community education towards acceptance should not be used to replace or divert attention from the need to remove barriers to activities and participation in tangible and measurable ways and the need for strong, enforced anti-discrimination legislation.

Offences motivated by prejudice against people with disabilities (discrimination, exclusion, vilification, hate crimes) should be prosecuted on the same basis as offences motivated by racial prejudice.

Australia's indigenous people also tend to have a higher rate of disablement,* such as hearing and vision limitation, largely due to such factors as higher rates of childhood infections and the ill effects of poverty and discrimination. Chronic illnesses such as diabetes also tend to occur in these populations at an earlier age than is common in the general population. Here, too, disability cannot be separated from or tackled in isolation from its social context.

Gender

While people with disabilities are stigmatised and discriminated against, women with disabilities are likely to be even further disadvantaged. Women are generally poorer, more often abused, and may be limited in their social roles. Girls and women have problems with self-esteem and body image that are increased by the experience of disablement. Limitations on participation may be seen as less significant for women, and funding from families and governments to enable participation may be less. Here, again, participation must be facilitated, with gender equity as the goal.

Disablement Strategy

Disablement strategy must operate within a framework that can take account of these issues of equity and disadvantage. People go through a series of life stages (as babies, as children, as adolescents, as workers, as older people) in a number of settings (family,

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* AIHW, 2004 *The Health & Welfare of Australia's Aboriginal and Torres Strait Island Peoples* 2003, Canberra, AIHW

school, work, the home). At each stage, and in each setting, the problems faced by a person with a disability can be reshaped by the same issues that trouble all of us, and can be worsened or smoothed away by the design of the setting.

There is a continuous interplay of environmental and genetic health determinants across the lifespan. Poverty can affect maternal nutrition, which can affect the disability rate for young children; malnutrition in children can affect health status as adults; family interactions can cause mental health problems for parents and children alike. Furthermore, people with sound social supports can cope better with trauma and loss.

The relationships between these factors can best be captured by a lifespan approach, which provides policy guidelines for disablement-related prevention, rehabilitation, and support in population groups from birth through to old age, within the context of families, organisations or institutions, communities, and the settings in which people live, work and play.

PUBLIC POLICY ACROSS THE LIFESPAN
Pregnancy and Birth

The health of women in pregnancy should be supported, and birth defects prevented, by policies directed at maternal nutrition (including supplementation to prevent such conditions as spina bifida), immunisation against teratogenic diseases such as rubella, and discouragement of underage pregnancies. Neither must old problems be removed only to give way to new technology-linked mistakes in such areas as assisted fertility and neonatal intensive care.

There is a danger, too, that new techniques in screening and genetic engineering may be misused to fuel prejudice against people with developmental disabilities. All such developments must take into account the need to avoid such stigmatisation. While women must retain the right to control their own bodies, the prenatal diagnosis must be structured so as to minimise prejudice and the pressure to conform. People with disabilities should participate in genetic counselling systems.

The right of women to self-determination, including reproductive freedom, is compatible with the right of individuals who have a disability to equality with others. The right to self-determination will be enhanced if women are allowed to decide whether or not to have prenatal screening, or to have an abortion when disability is identified, and if there is

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available to them appropriate support to raise a child with a disability. The decision whether a female should have an abortion should be not be influenced by the limitations to participation that a child might experience – limitations caused by the failure of society to tackle barriers and provide support for needs. There is a need for a wider debate on the issues involved in the selective termination of children with disabilities.

Nutrition in infancy should be adequate to enable normal development, and deficiency diseases resulting from insufficient iron, iodine or vitamins must be eliminated. Early diagnosis of developmental impairment needs to be encouraged and intensive compensatory services instituted within regular childhood services.

Infants and children with disabilities currently have comparatively high mortality rates, partly through the effects of their conditions and partly due to discriminatory medical practices. This differential must be eliminated.

Support programs, including carer self-help programs, should be provided for parents with special needs. Education of parents with children at risk of abuse should include support systems and information regarding specific disabling and handicapping conditions.

Childhood

Families cope with the strain of a child with activity limitation with varying degrees of success. The extent to which in the particular case the strain will cause familial dysfunction depends on an interwoven combination of individual, familial, socio-cultural, and historical factors. For families who have difficulty coping, support should be available to reduce family stresses.

Children with disabilities are at increased risk of abuse[2] (and abused children are at greater risk of disability), and measures should be taken to address this. Environmental contaminants such as lead that affect normal development should be removed. Immunisation against childhood diseases should be encouraged to reduce disablement. Childhood development must be directed not simply at a person's physical habilitation but at their participation in the civic and socialising experiences of their community.

Adolescence

As participation in the community is a human right, measures for dealing with activity limitation by removing or isolating persons with disability from society are misguided.

[2] Tomson, A., 1996, *Child Meltreatment and Disability, Issues in Child Abuse Prevention,* 7, 1-11

All children are integral members of their society who should have the same opportunity to experience socialising forces as their peers. Segregated education needs to be phased out in the minimum time, and children accommodated in the unsocial and unhealthy environment of institutions should be removed from them. The institutionalisation of children fosters stigmatisation and prejudice, reduces a child to a medical diagnosis, and inhibits participation.

Schools need to provide adequate support for people with activity limitation to enable maximum participation. Schools should also work to reduce societal prejudice against disability, and the education system should deal with the notion of human imperfection and the necessity of accepting difference.

Schools needs to empower all students, including children with disabilities, by helping them to develop skills and a healthy level of self-esteem, so that despite feeling at times impotent in the face of overwhelming forces they are able to exercise a significant degree of control over their place in the world. No limiting assumptions should be made about the abilities of any child. All children should be provided on a non-discriminatory basis with any special services necessary to enable them to attain their maximum development.

Adolescents whose ability to participate is restricted have a right to assistance which as far as possible removes the barriers.

Self-esteem is a key element in good mental health, and every effort must be made to reduce damage to the self-esteem of people with disabilities arising from prejudice, stigmatisation, and segregation. Physical disability increases the risk of depression, and depression increases the risk of mental illness.

Depression is among the most significant causes (and results) of disability, and often it appears first in adolescence: early intervention and prevention has been shown to reduce the risk of suicide. Services for the prevention of mental illness and the promotion of mental health should be incorporated in education systems and family services.

Education in adolescence on the risks of smoking, alcohol abuse, unsafe sex and poor diet can set patterns in later life that minimise disease and disablement. Injury levels, particularly road injury levels, need to be lowered. Interpersonal violence, a major risk factor in this age group, can be reduced by educational and social policies. Trauma rehabilitation needs to be given a high priority.

Working Age

In the past, people with disabilities have had the worst employment statistics of any group in society, and the work they get is usually poorly paid and low in status. Action should be taken to remedy this. Assistance should be provided to people with activity limitations who seek employment to identify the area of activity where they feel their talents can best be used. Governments need to ensure that there is reasonable accommodation in the workplace to the special needs of workers with disabilities. People injured at the workplace need to be assisted to return to work.

The workplace ought to be made a safe environment in order to reduce the risk of work-related disability. Lifelong education and intervention programs should be in place to assist people to avoid risks of disablement through trauma, illness or lifestyle.

Alternative activity programs should be provided to further the personal and vocational development of those unable to find employment. Society should also recognise the contribution made by people not in the work force, and self-esteem should not be linked to employment status (a measure that would improve the mental and physical health of unemployed people as well as people with disabilities).

Special assistance should be provided to people with chronic conditions such as diabetes to minimise the incidence of secondary impairment such as visual limitation or limb amputation.

Older Age

Ageing is an inevitable life process. The physical and mental changes that accompany ageing should be dealt with in a sensitive and respectful way. Activity limitation is a necessary incident of ageing, and presents a challenge to society to encourage the aged to maintain their participation in community and social activities. Ageing is a natural condition which should be neither medicalised nor stigmatised.

Older people are at greatly increased risk of further limitation through avoidable injury (falls and road trauma), avoidable sensory impairment (diabetic retinopathy, cataracts, deafness) and avoidable mental illness (depression, some dementias). The limitations of ageing are not different in kind or in significance from the problems faced by people with disabilities and chronic illnesses in other contexts, although some people with disabilities may experience the onset of the disorders of aging earlier than the general population.

The problems of an ageing population will be easier to deal with through a system that recognises and identifies needs in these areas and has designed its procedures to facilitate participation by all citizens without exception. Assistance needs to be provided on a non-discriminatory basis to allow people to cope with adjustment to and compensation for activity limitation.

Towards Full Participation

One of the most acute and the most limiting conditions internalised by people with disabilities is low self-esteem leading to learned helplessness and a loss of a sense of control. In this area self-worth is a fundamental element in maintaining good health, and any stigmatisation has severe consequences in mortality and morbidity. Prejudice must be combated, both in the media and across the community, whenever it appears.

People stigmatised as disabled have until recently been among the most disadvantaged in society. As a group people with disabilities have the least education, the highest unemployment rate, and the worst health facilities, and the poorest health.

Policy on disablement must recognise that the well-being of people with disabilities can be improved substantially only by removing barriers to participation in education, employment, housing, transport, recreation, urban development, and income security. A coherent public policy on disablement will require a commitment from all sectors. Full participation is impossible without appropriate accessibility policies. Disablement issues must be integrated into planning in all areas of government responsibility.

Conclusion

A full life for people with disabilities can only be achieved if current physical, social and political barriers are removed to allow their full participation in the whole life of the community – when people with disabilities, too, can join in Martin Luther King's dream -

> *When we let freedom ring, when we let it ring from every village and every hamlet, from every state and every city, we will be able to speed up that day when all of God's children, black men and white men, Jews and Gentiles, Protestants and Catholics, will be able to join hands and sing in the words of that old Negro spiritual, "Free at last! Free at last! Thank God almighty, we are free at last!"*

Dr Rhonda Galbally   AO

*R*honda Galbally AO has focussed her life's work on making a difference for a more equitable society. Her dynamic leadership in creating new solutions for community organisations is consolidated by her vast experience in social policy development. Rhonda is currently the CEO of the first Australian social investment company Our Community - building capacity to strengthen community www.ourcommunity.com.au

Previously Rhonda established the Australian International Health Institute (Faculty of Medicine, University of Melbourne). In that role she initiated the Asia Pacific hub at the University of Melbourne for the Bill and Melinda Gates Foundation Child Vaccination Program. Rhonda began the Victorian Health Promotion Foundation (VicHealth), the first body in the world to use a dedicated tax on tobacco for innovative health promotion. Prior to that Rhonda was the founding CEO of the Australian Commission for the Future, the executive director of the Myer Foundation and the Sidney Myer Fund. Rhonda is on numbers of Boards; she is the Chair of the Royal Women's Hospital, the Disability Advisory Council of Victoria and Patron of Orygen - the Youth Mental health Centre and also of the Sustainable Living Foundation.

Rhonda's new book has just been released: Just Passions - the Personal is Political, published by Pluto Press. Just Passions is about the major social movements in Australia – their history and the future and most of all it is about how to make a difference told through Rhonda's own stories

Sir John Quick

*J*ohn Quick was born in Cornwall, England in 1852. In 1854 his family migrated to Australia; his father died shortly thereafter.

At age 10 he entered the workforce, undertaking various manual jobs in mines then progressed to journalism. His drive for self improvement led him to complete a law degree at the University of Melbourne (1874-77) and in 1882 he was awarded a Doctorate in Law.

At this time, Sir John Quick was in charge of the Age Parliamentary staff. He entered politics himself in 1880, winning the Legislative Assembly seat of Sandhurst (Bendigo), which he held until 1889.

Quick's public support for Australian Federation commenced with an 1882 speech to Parliament. As a delegate from the Bendigo A.N.A., he attended the 1893 Corowa Conference where he presented the famous resolution which took Federation's fate away from Parliaments, and gave it directly to the people via elections for representatives and a referendum on the draft Constitution. He wrote the Enabling Bill needed for these stages to occur and also wrote a booklet, *A Digest of Federal Constitution* (1896), to help educate the public.

Throughout the two referenda campaigns of 1898 and 1899, he addressed numerous public meetings.

Quick's work for Federation was recognised with the award of a knighthood in 1901.

He was elected unopposed as Bendigo's first Federal M.P., holding the seat until 1913.

The Sir John Quick Bendigo Lecture has been established to revive the memory of this self-made man who had the forethought and perseverance to promote Australia's union. Quick himself referred to his long devotion to Federation as a "public duty" he had to perform. Sir John Quick deserves to be recognised as a "Father" of Australian Federation.

Written by Michele Matthews, BA(Hons) Melb, DipEd LaT

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