

Downward Spirals: disability and health costs as contributors to poverty and imagining ways forward

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Abstract

Low socio-economic status has a profound affect on the health and wellbeing of individuals. As a society, there is a need to focus attention on this cohort and address its needs through appropriate funding and services. The manifold barriers which limit the full participation of women with disabilities in communities results in our gross over-representation in the lowest income quintile. The 'fact' of disability is not a health issue but largely a societal one. Taking into account the gender and disability discrimination, this paper examines the impact of low income on the health outcomes of women with disabilities. Women with disabilities need to be able to manage their complex health needs in a cost-effective ways. All these factors must be integrally incorporated into the proposed National Women's Health Policy.

Keywords

Gender Disability discrimination low socio-economic status barriers to health

Acknowledgement

Before starting I would like to acknowledge the Mouheneener people, the traditional owners of the land on which we meet today, and to salute their elders past and present, and pay my respects to any other Aboriginal and Torres Strait Islander people who are here.

Introduction

The title of my talk reveals a chicken-and-egg-type dilemma for women with disabilities. Do our health care costs push us over a precarious edge into poverty, or is it our extreme poverty which locks us out of attending to our health care needs.

I would like to draw our attention to a World Health Organisation (WHO) definition of Health, articulated over sixty years ago, and quoted by Women With Disabilities Australia (WWDA) in its submission to the discussion framework for a National Women's Health Policy¹:

"Health is the state of complete physical, mental, and social wellbeing and not merely the absence of disease or infirmity. The enjoyment of the highest attainable standard of health is the fundamental right of every human being without distinction of race, religion, political belief, economic or social condition² and indispensable for the exercise of other human rights³."

However, I contend that this fundamental right to health and wellbeing will be unattainable for women with disabilities unless there is simultaneous policy attention paid to the state of poverty in which too many of us subsist.

In fact, an almost as ancient, United National Development Programme (UNDP) statement about poverty made 30 years ago, draws attention to the relationship of poverty and health (UNDP, 1997, p. iii)⁴. It states that:

“Poverty has many faces. It is much more than low income. It also reflects poor health and education, deprivation in knowledge and communication, inability to exercise human and political rights and the absence of dignity, confidence and self-respect.”

Women with disabilities do not need to be reminded that poverty has many faces. The relationship between gender, disability, poor health and poverty is very strong. The reality for many of us is that poverty first robs us of our dignity, confidence, self respect and with that the ability to maintain any degree of good health and wellbeing. To a large extent, we are unable to exercise our human and political rights. Unless all aspects of this nexus are addressed as part of a women’s health policy, there will be little hope for raising the health status of women with disabilities in this country.

For women with disabilities, it is tragic that in Australia we still use economic rather than social indicators to measure or describe poverty, and thus we do not adequately address all its facets, especially its relationship to health. In addition, if we are to take a human rights approach to health policy then we must put greater focus on all the societal factors which currently contribute to poor health outcomes for women with disabilities.

Socio Economic Determinants of Health

In fact, the concept that health was more than the administration of medical treatments can be said to have begun in the mid nineteenth century with the work of Engels and others⁵. Within and across nations, the inequities which are found in economic and political structures give rise to inequities in living conditions with consequent effect on the health and wellbeing of individuals. Within Australia, women with disabilities are one of the groups most excluded from the health system by poverty and a range of social factors.

Although you may now take for granted that these socio-economic determinants affect our health and wellbeing, it was as recently as 2005 that WHO set up a special Commission on Social Determinants of Health (CSDH). The CSDH seeks to promote global understanding of the social determinants of health based on a shared belief in social justice and human rights. No Australian government would argue against this, but to date, no government policy in this country has its true basis in human rights and social justice. It is WWDA’s belief that the application of these twin perspectives must be used in our national context to address the health and wellbeing of women with disabilities. Otherwise the reality that women with disabilities are in poorer health, and die younger than their non-disabled counterparts will not be reversed and these largely avoidable health inequities will persist. Other countries have embraced the concept of tying policies directly to human rights. For example, the Scottish Government used the Convention on the Rights of the Child as a basis for its homelessness policy⁶ and in acknowledgement of the inverse relationship between observance of human rights and poverty.

Macro and Micro-economic factors

To some degree the poor health outcomes experienced by women with disabilities in Australia arise as a direct result of government policies at a macro-economic level. To some extent their poor health is more affected at a micro level, where attitudinal barriers, combined with lack of access to the built environment, and inevitable economic constraints impose limits on the ability of individual women with disabilities to engage in maintaining optimal health and wellbeing⁷. In both cases, women with disabilities are being affected by the inescapable intersection of gender and disability discrimination. The additional discriminations which arise as a result of race, sexual preference, and country of birth, add

an extra layer of exclusion from the health system. To this must also be added the marginalization which occurs because of age (both disengaged young women with disabilities and senior women with disabilities) or the added discrimination of living outside our urban centres.

To look more closely at health policy and women with disabilities, it is necessary to look at the macro-policy picture. Very early in the current government's term, the Council of Australian Governments (COAG) signed on to a number of national endeavours. Amongst these a National Reform Agenda has been agreed upon. Included in the NRA are 6 National Agreements which contain the outcomes, outputs and performance indicators for both Commonwealth and the States/Territories on the distribution of specific purpose payments (SPPs) for the delivery of services across the relevant sectors. These Agreements cover healthcare (\$11.2 billion allocated for SPPs in 2009-10), disability (\$0.9 billion), schools (\$9.7 billion), skills and workforce development (\$1.3 billion), affordable housing (\$1.2 billion)⁸, and Indigenous reform (\$3.6 billion)⁹. In healthcare, spending is growing at a faster rate than GDP, and this will accelerate with the ageing of the Australian population.

Despite the current Australian Government's laudable commitment, additional disability funding and some measure of reform, it is still a drip-fed sector, with only a small proportion of total GST allocation given to the State and Territory disability services (see Figure 1).

When the social determinants of health are considered, all of these National Agreements are pertinent to raising the health status of women with disabilities. Within each agreement, women with disabilities need specific programs to improve our access to education, employment, housing and disability services. Only through improvements in all areas will our health and wellbeing be also improved. For indigenous women with disabilities there is particular need for targeted programs under all 6 National Agreements. However, of interest in today's context are the National Disability Agreement (NDA)¹⁰ and the National Healthcare Agreement (NHA)¹¹.

Under the NDA, all governments agree that:

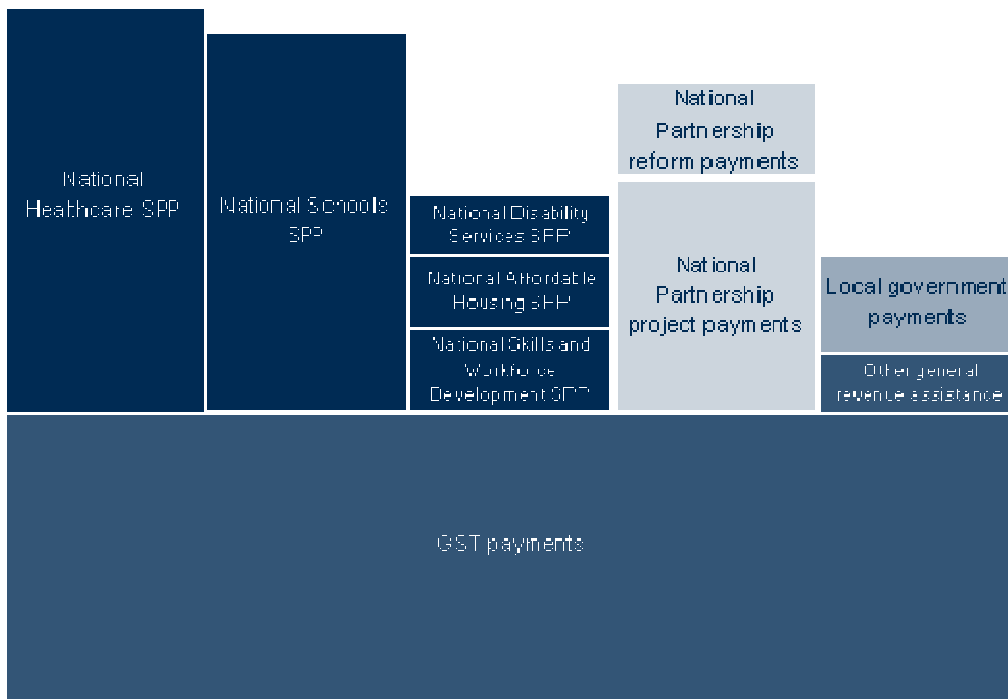
“people with disability should achieve economic participation and social inclusion with choice, wellbeing and the opportunity to live as independently as possible, with families and carers being well supported in their roles.”

Importantly the NDA carries a commitment to the collection of data, reported on an annual basis. Reforms will be made based on this data (NDA p.5). However, because the initial agreement only came into effect on 1 January 2009, most of the data collection mechanisms are not yet in place. It is important for all work under the National Reform Agenda that data collected is disaggregated, and made freely available to non government organisations.

Under the NHA, all governments agree that the healthcare system must:

“strive to eliminate differences in health status of those groups currently experiencing poor health outcomes relative to the wider community, with timely access to healthcare services based on need rather than ability to pay.”

Figure 1: Schematic of payments to the States in the new financial framework¹²



The NHA specifically states a commitment to ensuring that people with complex health needs can access comprehensive, integrated, coordinated services. These words have an ironic ring for women with disabilities, whose health status is chronically lower than that of the general population, and for whom timely access to services has been a pipe dream.

Health as a Human Right

For women with disabilities, the lack of data about any aspect of our lives means that policies and programs consistently overlook our particular situation. This lack was noted by the Committee for the UN Convention on the Elimination of Discrimination Against Women (CEDAW). In its response to the Australian Government’s Fourth and Fifth Reports “*Australian Women*”, it stated:

“[The Committee] also regrets the absence of sufficient information and data on women with disabilities.¹³”

and further stated that:

“The Committee requests the State party to include adequate statistical data and analysis, disaggregated by sex, ethnicity and disability, in its next report so as to provide a full picture of the implementation of all the provisions of the Convention. It also recommends that the State party regularly conduct impact assessments of its legislative reforms, policies and programmes to ensure that measures taken lead to the desired goals and that it inform the Committee about the results of these assessments in its next report.¹⁴”

The obligations of CEDAW are reiterated in many of the other international covenants and conventions to which Australia is a party.

Women with disabilities need to be able to control all aspects of their health, particularly their own fertility, and their sexual and reproductive health (Beijing Platform for Action and

Declaration 1995¹⁵). At present women with disabilities are still largely misunderstood and ignored in breast and cervical cancer screening. In a 2009 report from BreastScreen Australia¹⁶, women with disabilities were said to have CHOSEN NOT to present for mammograms because they PERCEIVED they would have difficulties in physically accessing the equipment. This paints us as churlish non partakers of a government 'gift' to women. The same report named 'transport' as one of the limiting factors for other groups with low participation figures. The irony of being able to make this statement in the face of failing to collect statistics is not lost on WWDA. Moreover, BreastScreen Australia seems to assume that all women with disabilities are in wheelchairs, have unlimited disposable income to pay for carers and taxi transport, and just stubbornly refuse to come!

WWDA contends that so long as women with disabilities do not have better incomes and greater control over their finances, they are at risk of not presenting for any medical consultations or screening programs, and at risk of not seeking early intervention when symptoms manifest. Poverty itself exposes a woman with disabilities to more situations of discrimination, more situations of risk, and greater vulnerability to a wider spectrum of violence, abuse and neglect.

Global Financial Crisis

The lack of financial security affecting women with disabilities is in large part due to the workforce structure of our society. The employment (and therefore financial) situation for all women in Australia has deteriorated over the last decade. For women with disabilities, their employment situation continues to be desperate. The increased casualisation of the workforce has disproportionately affected all women, but for women with disabilities, it has been nigh on disastrous. Obtaining employment is difficult. The last publicly available figures from the 2003 ABS Survey of Disability, Ageing and Carers¹⁷, puts the workforce participation rate for women with disabilities at 46.9 percent (13 percentage points lower than that of men with disabilities, and 18 percentage points lower than the figure for the non-disabled population). Women with disabilities are over-represented in short term, low paid, casual, part-time jobs.

Only approximately 9% of women with disabilities are employed full time (compared to 21% for men with disabilities). In contrast 11% have part time employment (compared to 6% for men with disabilities). The unemployment rate of disabled women in 2003 was 8.3% compared to 5.3% for non-disabled women (ABS 2004).

In the early days of the Global Financial Crisis (GFC), it was predicted that unemployment rates for the general population would rise to over 8%. Such a horrific rate did not faze us. It approximates to the usual unemployment rate experienced by women with disabilities. Internationally it was recognized that the GFC would impact disproportionately on people with disabilities, and governments were urged to include special measures for people with disabilities to address the crisis¹⁸. There was no evidence of this in Australia. The current re-focus on gender inequalities in the workplace and the widening gender pay gap, somewhat bypasses women with disabilities. Our employment situation continues to be desperate.

Extending my earlier analogy of chicken-and-egg problems, these statistics on employment highlight the need to examine the sorts of courses that women with disabilities are selecting if they go on to further education after leaving school. In university education, women with disabilities overwhelmingly choose Social Studies related courses, and miniscule numbers enter engineering and ICT compared to their male counterparts with disabilities. These are similar trends to those found in the non-disabled population. The situation in Vocational and

Employment Training (VET) is worse with high numbers of women with disabilities found in the NON vocational life skills courses. It is no wonder that we are clustered in the vulnerable end of the workforce.

It also means that large numbers of us are reliant on welfare payments. Currently those receiving the single full DSP of approximately \$350 per week¹⁹ (\$18,000 pa) are right on the Poverty Line²⁰. This amount is only 64% of the National Minimum Wage (NMW)²¹, and a mere 30% of average weekly earnings²².

Poverty, diet and non communicable disease

From this position of extreme poverty many negatives flow. Witness the strong correlation between poverty and poor diet. Worldwide amongst the poor there is increasing reliance on foods rich in fat, sugar and salt. Accompanying this are high levels of alcohol, tobacco and other substance abuse. Coupled with lack of incentive to exercise, lack of exercise associated with getting to and from work, these consumption patterns entrench a sedentary lifestyle with increased propensity for chronic disease. Although obesity is a problem across all socio-economic groups, there is a much higher incidence in the low income groups once a country's per capita income exceeds US\$2500²³.

Universally, it is useful to focus on women's income when assessing a family unit's ability to weather financial crises. The effect of a financial crisis on a household containing a woman with disabilities is great, because she is least likely to be able to obtain work. In a crisis, it is a commonplace strategy for a stay-at-home woman to seek work or to increase her hours of work. This is not a likely solution where that woman has disabilities. Conversely, where the woman with disabilities was already in the workplace, she is in a vulnerable position and most likely to be amongst the first put out of work, when the financial crisis worsens. Thus the GFC, even in Australia where its affects were minimal, disproportionately affected households where a woman with disabilities was living.

Let us look closer at yet another health consequence of poverty for women with disabilities. In high-income countries 80% of morbidity in adult women is attributable to non-communicable disease (NCD) such as cardiovascular conditions, cancers, mental neurological and substance abuse disorders and associated disabilities. The incidence of NCDs in women with disabilities, in addition to their primary disability, is thought to be higher than amongst non disabled women. However, we lack data, and the impact of NCDs on women with disabilities must be researched and addressed in the NWHP.

The ACROSS Community Sector Survey of 08-09²⁴ showed a 19% increase in calls for assistance in the first year of the GFC. This included calls for additional disability support services, mental health counselling, funding to pay bills, emergency beds etc. In fact, Telstra's Low Income Management Advisory Council (LIMAC) research²⁵ showed that the hard times hit low income people the hardest, and they are taking longer to recover. In 2008-09, 20% had sudden health problems, and 18% could not manage to pay their phone bills. The fact that 34% of those who sought bill assistance were recipients of the Disability Support Pension shows the impact of the GFC on all people with disabilities. Yet, in times of crisis, the phone becomes even more of an essential service, and LIMAC recorded that that there was an accompanying 50% increase in phone usage with calls to doctors to cope with the health problems which arose, calls to look for work, contacting family, and finding assistance services.

Unfortunately in welfare reform, conditionality and compulsion are more common characteristics of government anti poverty campaigns. Some welfare policies and programs

seem to regard poverty as some sort of morbid lifestyle choice. Rather, we need to focus on socially and legally guaranteed entitlements. All too often Human Rights are only considered in terms of civil and political rights. But it is clear that in the context of rights we should measure capacity to participate in the community and 'equality' rather than income levels as indicators of poverty.

Conclusion:

Women with disabilities wish to claim access to good health care as a Human Right, and to a standard of care which is not limited by low income, or overlooked because of our lack of status in society.

There is a need to adopt CEDAW as the basis for NWHP, similar to the manner in which other countries have based their policies on relevant human rights treaties. The NWHP must be developed so that the needs of the poorest individuals are considered first, and all programs must be based on sound evidence.

The NWHP needs to acknowledge and address the link between poor health and poverty. Coordination across government departments is a key and the NWHP also needs to be linked to accessible public transport plans, and also to include emphasis on the development of e-Health initiatives which will reduce the need for transport. Community and home visit programs could strengthen connectedness and reduce the isolation that women with disabilities experience. There is a need to work at the community level in planning, implementation, monitoring and evaluation of health programs.

Encapsulated in a 2007 joint publication from WHO and the Office of the High Commission for Human Rights²⁶, a human rights basis for health services will have these characteristics:

(1) Available: functioning public health and health care facilities, goods and services, as well as programmes, which are available in sufficient quantity.

(2) Accessible: health facilities, goods and services which are accessible to everyone without discrimination, within the jurisdiction of the state party. Accessibility has four overlapping dimensions: non-discrimination, physical accessibility, economic accessibility or affordability, and information accessibility.

(3) Acceptable: all health facilities, goods and services must be respectful of medical ethics and culturally appropriate, sensitive to gender and life-cycle requirements, as well as designed to respect confidentiality and improve the health status of those concerned.

(4) Quality: health facilities, goods and services must be scientifically and medically appropriate and of good quality.

Women with disabilities must be included - the disability movement demands that there be "Nothing about us without us". Women with disabilities must have places at the consultation tables in all stages of the development and implementation of the NWHP.

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