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**Human Rights and Equal Opportunity  
Commission - *Inquiry into Employment and  
Disability.***

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**April 2005**

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## About ACTCOSS

ACTCOSS acknowledges that modern day Canberra has been built on the traditional lands of the Ngunnawal people. We pay our respects to their elders and recognise the displacement and disadvantage they have suffered since European settlement. ACTCOSS celebrates the Ngunnawal's living culture and valuable contribution to the ACT community.

The ACT Council of Social Service Inc. (ACTCOSS) is the peak representative body for not-for-profit community organisations, people living with disadvantage, and low-income citizens of the Territory. ACTCOSS is a member of the nationwide COSS network, made up of each of the state Councils and the national body, the Australian Council of Social Service (ACOSS).

ACTCOSS' objectives are representation of people living with disadvantage, the promotion of equitable social policy, and the development of a professional, cohesive and effective community sector.

The membership of the Council includes the majority of community based service providers in the social welfare area, a range of community associations and networks, self-help and consumer groups and interested individuals.

ACTCOSS receives funding from the Community Services Program (CSP) which is funded by the ACT Government.

### **Contact Details**

Phone: 02 6202-7200  
Fax: 02 6247-7175  
Mail: PO Box 195 Civic Square ACT 2608  
E-mail: [actcoss@actcoss.org.au](mailto:actcoss@actcoss.org.au)  
WWW: <http://www.actcoss.org.au>  
Location: Jamieson House  
43 Constitution Avenue  
Reid ACT 2612

Director: Ms Ara Cresswell

Senior Policy Officer: Ms Karen Nicholson

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## **Human Rights and Equal Opportunity Commission**

*Inquiry into equal opportunity in employment and occupation for people with a disability.*

*Terms of Reference.*

*Dr Sev Ozdowski, Human Rights Commissioner and Acting Disability Discrimination Commissioner, will conduct on behalf of the Human Rights and Equal Opportunity Commission and pursuant to sections 31(a)(b)(c) and (e) of the Human Rights and Equal Opportunity Commission Act 1986 (Cth), an inquiry into equal opportunity in employment and occupation for people with a disability in Australia.*

*The purpose of the inquiry is to:*

- *identify existing systemic barriers to equal employment opportunity for people with disabilities;*
- *examine data on employment outcomes for people with disabilities including workforce participation, unemployment and income levels; and*
- *examine policies, practices, services and special measures implemented to advance equal employment opportunities for people with disabilities.*

*The scope of the inquiry includes:*

- *Commonwealth government as an employer and service provider; and*
- *private sector employers.*

## INTRODUCTION

The ACT Council of Social Service is not putting itself forward in this review as the voice of people with disabilities. Our perspective is drawn from the development of systemic advocacy across a wide range of policy areas, including disability, welfare reform, employment disadvantage, poverty, mental illness, drug and alcohol misuse and discrimination. We are confident that the Human Rights and Equal Opportunity Commission (HREOC) processes will proactively seek out and consult with people with disabilities within the community, as well as speaking to the people who work in the areas of service delivery and support for people with disabilities.

What ACTCOSS believes it can comment on with most authority is the area of systemic disadvantage, unmet need in human services and the community understanding of disability and its manifestations. Under normal circumstances, our practice would be to widely consult with consumer groups within the ACT, and then forward those comments in our submission. However, given the large amount of consultation that has taken place in the ACT on disability issues over the past few years, and the fact that ACTCOSS is encouraging its members and affiliates to directly submit to HREOC, we have departed from this process.

Overall, our position is that removal of the barriers that people with disabilities face in entering the labour market starts with meeting the need for human services which facilitate participation in the wider community. These needs are articulated well by the consumers and their representative organisations and should be discussed with these groups under the auspice of this inquiry.

A corollary to this position is that the social model of disability must become the norm in public discourse. Whilst disability continues to be described in medical terms, the idea persists that people are living with a curable disease that can be overcome with technology and medicine. Under the medical model of disability solutions also become individualised and move away from the systemic. Changing the prevailing mindset will involve community education and action by politicians and other community leaders. This would be assisted by the return to a full-time, rights-based disability Commissioner who represents the interests of people with disabilities.

The other issue that must be addressed is the notion that often dominates social policy discussion on this issue: that people with disabilities who are not currently in the workforce should be provided with low-skilled jobs that have limited or no prospects for career development and promotion. Disability does not mean lack of ability, and many people with disabilities achieve the same outcomes and

have the same ambitions for their working life as others in the community. Providing programs to enable them to obtain paid employment does not mean creating dead end jobs or providing subsidies for employers to put someone into a position that has no prospect of meeting the occupant's ambitions or need for skills development.

On this matter, we would like to see some clarification from HREOC as to the definition they are using in this inquiry for the term "occupation". In ACTCOSS' view, an occupation can be a career, however, there is potential for other interpretations.

ACTCOSS is pleased that this important issue is continuing to receive attention at the highest levels of social policy discussion. We wish to point out, however, that there have been a large number of reviews and inquiries into all levels of disability service over the past few years. ACTCOSS urges HREOC to ensure that the hard work and time given by people with disabilities to these reviews are not ignored simply because this inquiry has focussed on employment, rather than service provision and the wider issue of social participation.

## People with disabilities and the community

*"All animals are equal but some animals are more equal than others."  
George Orwell, Animal Farm, 1945.*

HREOC has entered the debate about disability and workforce participation at an interesting stage in public policy development. The Federal Government has devoted considerable resources to determining how to increase workforce participation rates among people who are seen, traditionally, as being reliant on income support, such as single parents and people with disabilities.

ACTCOSS is pleased that HREOC sees this as a priority, but is concerned that this review continues the practice of previous inquiries by asking people with disabilities for the solutions to the problem of their employment status. Whilst the review has the scope to look at Commonwealth and private sector employers, in one sense the review starts from the wrong place. In ACTCOSS' reading of the terms of reference, the problem is still attached to the person with a disability, even as the inquiry looks for the systemic causes of unemployment among people who identify as having a disability.

The current discussion also focuses on participation in an existing market. The terms of reference could have been expressed as a function of the employment market – for example "What are the features of the current employment markets in Australia that prevent people with disabilities progressing in the workforce?"

Even that may be precipitate. Before we consider what barriers to the workforce exist for any particular cohort there needs to be an analysis of what services and supports are needed to enable people with disabilities to engage in their community. There have been several reviews of services in the ACT in the past few years, and the main message of these has been that there are insufficient services to allow people living with disadvantage (which includes poverty, disability, chronic illness, mental health problems, drug and alcohol misuse, communication difficulties, etc.) to fully access the community they live in. One of the more recent is the Australian Institute of Health and Welfare (AIHW) study for the ACT Government "Addressing Disadvantage" project in 2003 (AIHW catalogue HSE23), "The need for, and provision of human services in the ACT".<sup>1</sup>This

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<sup>1</sup> The companion studies in the "Addressing Disadvantage" Project were an analysis of poverty in the ACT by NATIONAL Centre for Social and Economic Modelling (NATSEM) and a survey of non-government service providers by ACTCOSS. The ACT Government did its own analysis of Government-provided services. We recommend these studies to the HREOC. (<http://www.cmd.act.gov.au/about/publications.shtml#Reviews%20and%20Reports> – under Reviews and Reports – all four volumes are grouped together at the bottom of the page)

work shows that demand has not yet been met for most basic community access services.

The recent increase in the use of Individual Support Packages (ISPs) in the ACT is one way the ACT Government is tackling the problems of disability support meeting individual needs. Yet problems persist - of over 200 applications for ISPs, just over 50 were allocated. Many people with high support needs were not able to obtain an ISP, and continue to rely on generic services that may not meet their particular needs.<sup>2</sup>

The recently released Australian Community Services Survey 2005, conducted by the Australian Council of Social Service (ACOSS), shows that in the ACT, turnaway rates for community service consumers are still high, and there are particular problems with recruiting and retaining trained staff to provide these services (ACOSS, 2005).

The lack of adequate support means that some people with disabilities are unable to get out of bed at any set time, and must rely on the availability of personal care workers. This can disrupt life enormously, even if employment is not an issue. In other situations there may be a lack of appropriate transport to get people to regular therapy sessions or to suitable venues for daily exercise. Access barriers may include major fears or phobias, or the lack of appropriate technology or interpreter services.

Many people with disabilities are unable to do their own shopping, manage commercial transactions or participate in social activities because of access difficulties in the community. To prioritise participation in the workforce above supporting daily interaction in the community would, in ACTCOSS' view, misrepresent the need. We do understand that there are many people with disabilities who currently are in the workforce, and many more who are actively seeking paid employment. However, for many people, making a commitment to paid employment is not possible until they can be assured that they receive a level of appropriate services that allow them to participate in their community in a predictable fashion. The obvious comparison to this is the provision of childcare, and the expectation that care will be available, reliable and affordable.

Inextricably linked to this is the need to recognise the cost of disability. It is assumed that, once a person with a disability has paid employment, they no longer need social supports or financial reimbursement for the costs associated with accessing the community. ACTCOSS will leave the discussion of the marginal tax rate effect of changing from income support to wages to other groups, but wishes to make a related point. The cost of disability is

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<sup>2</sup> See Attachment 1, an example of one family's response to ISPs.

not recompensed by having a job that pays the person with a disability the same wage as other employees. A much higher income is needed to provide for the non-discretionary costs of disability, which can equal an additional \$10-\$30,000 per annum. ACTCOSS feels that the issue is well expounded on the Physical Disability Council of Australia (PDCA) website<sup>3</sup>

There are also issues of multiple disability, or disability combined with medical issues, which can mean multiple supports and comparatively higher costs. The permutations are infinite, and should be addressed on a case by case basis, in consultation with the person with a disability. Meeting the cost of disability is a major barrier to many people with disabilities being included in the community and participating in the workplace. ACTCOSS strongly advocates that there should be a right to an allowance that assists with meeting the cost of disability, independent of the employment status of the person with a disability.

***ACTCOSS' position on this issue: Equality of opportunity for work does not come until after equality of access to community life, which includes financial recognition of the cost of disability.***

## **Language and discussing disability**

ACTCOSS is concerned about the language used in the debate about participation of people with disabilities in the workforce, some of which falls into the trap of stereotyping.

In one question, employers are asked why they don't employ people with disabilities, with some of the fears that may be expressed from time to time cited as examples. Stating these as direct questions provides these fears with a legitimacy that they do not deserve. Rather than ask why you don't do something, the question, if it needs to be asked at all, should be framed in an empowering way: what services should be available to assist you to employ people with disabilities? The result would be far more creative than focussing on the negatives.

ACTCOSS also questions why this section has been included in the discussion, as the paper is prefaced with reference to the multitude of previous reviews that identified many barriers to employment for people with disabilities. Again, the discussion paper focuses on the individual, rather than systemic issues.

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<sup>3</sup> <http://www.pdca.org.au/cgi-bin/pdca/contents.pl>

***ACTCOSS' position on this issue: The language used and the way the paper is framed still asks individual people with disabilities and employers to solve the employment "problem".***

## **Who receives assistance in current workplaces?**

At present, "regular" participants in the "competitive" workforce get a lot of assistance to get to work and to contribute their skills – transport systems, accessible buildings and workplaces, suitable accommodation that allows them to be as self-sufficient as possible, school and care systems that attempt to accommodate their caring responsibilities, accessible technology such as phones, faxes, household cleaning appliances, shopping centres that allow them to self-select goods and other services that they require to meet their requirements for participation in the wider society. For most people, there is some choice about the consumption of these services and resources (leaving aside the problems associated with child care, which has parallels to the problems of services for people with disabilities).

In contrast, people with disabilities are expected to overcome access barriers and obtain paid work so that they can afford to be included in the community: a community that is designed around the needs of people who are mobile and otherwise able. The time deficits alone caused by this lack of access cannot be bought back by participating in the open workforce.

The dominant paradigm of community life and work has become more exclusive as we have adopted a car-based, commuter society that values private time and carries out much of its socialising in the work environment, or away from private residences. What this shift in community has done is to assign those who do not share that lifestyle or level of ability to the realm of "the other". People with disabilities are not visible, as they are not permitted to interrupt the commuter lifestyle: people using pension concessions can only access the cheapest bus fares if they travel "outside of peak times". Taxis that are licensed as wheelchair accessible are often not available at "peak times", with hearsay evidence being that non-wheelchair commuters are more profitable at those times.

***ACTCOSS' position on this issue: There needs to be wider recognition through discussion, legislation and regulation that workplace are increasingly reducing***

*accessibility, using the mantra of cost-saving and productivity to exclude people with disabilities.*

## **Medicalising disability**

This leads ACTCOSS to the larger issue of the dominant paradigm, the analysis of the current construction of disability as a medical problem, and the personalising of disability.

Gerard Goggin and Christopher Newell's "Disability in Australia: Exposing a Social Apartheid" (UNSW Press 2005) speaks eloquently about the "othering" of people with disabilities and medicalising their circumstances. An example of this was the 2003 review of Child Disability Allowance by Centrelink. The review asked parents to get a medical practitioner's assessment of their child's disability. As one parent put it, their child (who is autistic) does not suffer any health problems, and her doctor had never dealt with that aspect of her child's life. There was no capacity or preparedness for other disability professionals to provide an expert opinion – it had to be a GP. In earlier reviews a generic form was used to garner information from parents, including asking parents of children with Down's Syndrome if their child still needed ongoing support. "Cures" have not been identified in either area.

Many adults with disability have good general health. Some have medical complications that do require intensive support from doctors and other allied health services. However, as Goggin and Newell discuss, science has convinced the community at large that all disease and disability can be "cured". This then persuades that part of the community which does not experience disability to believe that this is the goal of all people with disabilities – to be cured. This flies in the face of evidence that disability rates have not dropped, and that some medical interventions are leading to higher rates of some physical, intellectual and mental conditions.

Every new discovery seems to lead to new claims that we have seen the end of disability and infirmity. Dr Karl Kruszelnicki, famous and influential for making science accessible for non-scientists via the ABC, claimed in 2004 that new stem cell research would see the end of death – everyone could live a life that was greatly extended from current longevity, in full health. The message that such pronouncements make is that the crippled can walk, the blind will see, and they only have to wait until we gather some more stem cells! As Goggin and Newell discuss at some length, well know people with disabilities, like Christopher Reeve, have perpetuated this idea that disability is a medical problem that is ultimately curable. While

“cures” may be found for some disorders and disabilities in the future, that does not remove the urgent need for services in the present.

ACTCOSS finds this a conundrum. With an estimated one in five people having a disability<sup>4</sup>, a large number of people with disabilities are already working and in touch with their local communities. Yet the wider community is not recognising people with disabilities among their friends, acquaintances, and colleagues, then recognising that people are being excluded from economic activity on the basis of disability.

Public education is needed to make the connection that disability is not a defining word that is applied to a certain cohort – it is a term that explains only one aspect of a complete human being. While we make the disability a personal, individualised, medical experience, we can deal with it in a personal, individualised, medical way. The individual is blamed for their disability, with a public perception that the person with a disability must take responsibility for their social isolation and living situation, not the wider community. This indicates a residual level of shame associated with disability that ACTCOSS believes must be dispelled, through leadership at all levels.

ACTCOSS believes that the situation for people with a disability in relation to their participation in the workforce will not change until the reviews of old ground stop, and action is taken. As was the case with women and the employment market, there needs to be support given to make people with disabilities visible among the workforce. This means promotion into high level positions in corporate and public sector life. It also means recognising the cost of disability and entrenching financial support for consumers to address this cost.

***ACTCOSS’ position: Immediate attention must be given to countering the medicalisation of disability, with more weight given to the idea of disability being a social construct.***

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<sup>4</sup> PDCA website, op cit.

## **Other issues that need to be actively considered**

### **Education**

A wide range of children with disabilities do not access relevant and appropriate education. While “special education” facilities are provided for young people with profound physical disabilities, many ambulatory young people progress to high school without formal recognition of their need to be taught in a way that takes into account their learning styles, and at a pace that meets their needs.

ACTCOSS believes that the HREOC would be assisted in this current investigation to review the information available on education systems and how they are dealing with disability. Particular attention should be paid to those children whose education is interrupted by ill health associated with a disability as this can make it difficult for young people to remain connected to the education system until year 12..

Similarly, with non-medical disabilities, such as Attention Deficit Hyperactivity Disorder (ADHD), autism and some behavioural disorders, students can miss out on opportunities to develop their workforce skills because of disrupted school attendance. Most employment programs offered in high schools and colleges have, in the past, focussed on helping young people who can meet the demands of school and work. While this culture is changing, the very nature of these programs mitigates against most students with disability participating in school to work programs, or obtaining the skills required for workplace participation. Instead, many young people with a disability are “managed” through to year 10 and 12 with no real expectation that they will achieve independent employment.

Others who are yet to manifest any recognised signs of disability have often also been overlooked. These young people (and their carers) also suffer because of an assessment that, because they don’t achieve at school, they aren’t capable of anything more than low skilled jobs in the workforce. That is, failure to achieve academically in mainstream educational environments equates to a lack of ability for workforce participation and promotion. One example of this type of labelling are young people with ADHD, a disability that may manifest itself in behavioural problems in adolescence.

As outlined in terms of workforce participation, people with disabilities need to have their educational needs recognised and met in a way that provides them with equity of outcomes with their peers in education, not uniformity of inputs.

***ACTCOSS' position: There is a need for increased study of educational expectations and programs for young people with disabilities to determine how we can best cater for the different learning rates of young people.***

## **Workforce health**

Over the past several decades there has been growing recognition that the expectations of increasingly competitive workplaces, with long hours, insecure employment, underemployment and increased use of contractors who bear their own insurance and other risks, are having a negative impact on the health of workers. Whilst research has long recognised the problems associated with unrealistic expectations of workplaces and the severe strains these put on employees, Governments do not facilitate a withdrawal from this form of exploitation. Flexibility in the workplace has been lost with the need to deliver increasing outputs under pressure – known euphemistically as “productivity gains”.

As risk (as understood in insurance and Occupational Health and Safety terms) is shifted more and more on to employers, they appear to be responding by trying to ensure that they lessen their obligations to their employees. For people with disabilities, this is compounded by the medicalisation of disability, so that employers see disability as a form of risk to be avoided.

Employment of people with disabilities, again, needs to be the function of inclusive practices and accessible workplaces. This means recognising that **all** workers need a workplace that meets their physical needs, is accessible, provides work that meets their expectations of a working life, uses their talents and skills, and values their contribution as individuals. Given that some workplaces actually contribute to the breakdown of worker health, there needs to be a concerted effort to ensure that working conditions do not cause or exacerbate illness, or exclude people because the workplace is not being managed to maintain the health of its workforce.

***ACTCOSS' position: There is a need to examine the links between workplace “reform” and the decline in employment opportunities for people with disabilities, as well as improved regulation of workplace practices that can lead to worker ill-health.***

## **Visibility**

Most discussion of employment and disability centres on employing “a person” with a disability. ACTCOSS believes the discussion should, instead, be about providing an accessible workplace that can provide meaningful work and accommodate all persons qualified for the jobs available. The groups that often are seen as needing “special” consideration include people with disabilities, those from Culturally and Linguistically Diverse backgrounds, Aboriginal and Torres Strait Islander people, women, carers, people with chronic illness, older workers, and many other people who can be “categorised” as non-regular workers.

People who are able-bodied often identify a wide range of issues that make participation in the workforce more or less compatible with their social and societal obligations. Employers need to be provided with competencies and training in identifying how to support all workers, not just in making special arrangements for people with disabilities. Some employees need recognition of culture in their working arrangements, for example the provision of facilities and time to pray. For others, it is recognition of their role in community organisations, perhaps as volunteer emergency service personnel, or as a carer. Quite a few workplaces, admittedly often in female dominated, low-skilled processing industries, make these types of adjustments without comment, but still see employing a person with a disability as somehow different.

Some industries (such as IT) have been able to develop flexibility around work hours, locations, days worked and physical environment, which means that they have the potential to have a more diverse workforce than other industries. Some of this flexibility and recognition of the nature of work may help employers think more flexibly about what constitutes an inclusive workplace.

ACTCOSS believes that to provide an inclusive workplace is to look at the work to be done, the skills required, and to then ensure that the person who has those skills is able to take up that position. Instead, we have workplaces where people are expected to fit into a pre-arranged structure and physical location, regardless of whether that is appropriate or necessary.

As such, people with disabilities are not visible in the workforce, except in being exceptions to “normal” employment practices. Or, alternatively, some workplaces that do have a higher number of people with disabilities are seen as being somehow “different” to normal workplaces. Some of these employers have received awards for providing an inclusive workplace. ACTCOSS believes, however, that every workplace should be inclusive.

There is also the issue of fear of discrimination within the workplace, particularly for people with acquired disability. It has been seen in some employment sectors in the past as being a career threatening move to admit to a disability in the workplace. This means that many disabilities that could be dealt with in the ordinary course of personnel management can become major issues, threatening employment stability.

There will be a need for leadership in turning the invisible into the visible. Not only do we need to provide an inclusive workforce that allows people with disabilities to gain employment, promotion and a fulfilling career, it will also be necessary to provide support for people who develop disability over time while in the workforce.

Part of the solution is a return to a more inclusive public sector. This includes providing a full-time Disability Commissioner who advocates and lobbies on behalf of people with disabilities. ACTCOSS believes that the Federal Government had abrogated its responsibilities by not providing a permanent Disability Commissioner, although we are pleased that the Human Rights Commissioner has been able to carry on this important work. We note that other important areas of discrimination representation have also been allowed to slide in recent years, and we are equally adamant that areas of inequality of rights need to be better resourced and supported.

Representation of consumers by consumers is important, as is having leaders who are also representative of the population at large. There has been little support of people with disabilities in the political process, nor is there very much evidence that policy debates on disability issues are being led by those who have the greatest knowledge of this area – people with disabilities.

Again, this is an issue of making the community inclusive, not defining work by the ability to perform at unsustainable levels of output, and ensuring that every person is able to have their workplace meet their needs in terms of being accessible, health and flexible.

***ACTCOSS' position: For people with disabilities to increase their workforce participation, there needs to be an increase in the number of people with a disability at all levels of community and economic life. This visibility aspect will require public sector agencies to lead by example and to provide accessible workplaces, with employment opportunities at all levels of their activity for people with disabilities.***

## Conclusion

ACTCOSS believe that there are a number of issues at stake when discussing employment of people with disabilities. We believe that society as a whole has a role to play in making the community accessible in the first instance, and then providing workplaces that recognise the skills and talents that individuals bring to their team to produce the desired or required outputs.

The first issue in this is to make accessibility a priority so that every person within the community can access all the benefits of that community. This means adequate transport, human services and the myriad of services and goods that are necessary to provide equity of access for people with disabilities. It also means accessible buildings and community facilities, so that people with disabilities can work where they choose.

The second issue is that funding should be available for all people with disabilities to provide them with the personal care or equipment needs for participation in the community. This, we believe, should take the form of a “cost of disability” allowance that is not means tested or workforce based.

The third issue is that people with disabilities need to be involved in all areas of human activity, and not relegated to “special” industries – they should be visible in the workplace. This means that the community, Governments and individual employers should not be looking at one-off modifications for specific individuals as a way to encourage people with disabilities to take up paid employment. The Federal, State and Territory Governments have a role in this, by leading with an accessibility plan that rolls out improvements that recognise that human beings come in all shapes and sizes, with a range of personal space needs and equipment requirements to perform the tasks associated with their jobs.

The fourth point ACTCOSS wishes to make is that employment for people with disabilities needs to fulfil more than just a time-occupying role. People with disabilities are entitled as a right to have meaningful employment that meets their need for personal development and challenge. This includes opportunities for career development and promotional opportunities. ACTCOSS believes that jobs for people with disabilities should not be commercial equivalents of sheltered workshops – opportunities should be available at all levels of economic activity.

This also requires the removal of educational barriers. ACTCOSS believes too many young people are “selected out” of the education

pool through non-flexible educational programs (eg minimum units), inaccessible facilities (takes 15 minutes instead of 2 to get upstairs by using the freight lift), and restricted access to resources such as computers. It is a community and Government-wide obligation to provide flexible learning pathways with assistive technology in the workplace, and in support of formal schooling.

## Attachment 1

The following letter appeared in the Canberra Times on Saturday, April 2, 2005. It is used here as an illustration of how some people are still being excluded from their communities by lack of support.

### Extra disability funding is falling short of demand

Sally Richards

Saturday, 2 April 2005

Lois Ford the executive director of Disability ACT states "this Government has an ongoing commitment to people with disabilities and has demonstrated this through the allocation of additional funding." (CT March 27, p16).

We already know that the additional funding falls a long way short of meeting the need.

Verbal commitment is easy; committed action is something else altogether.

Ford is right about the "low level of throughput" however. As long as we have babies and drive cars, just to name a couple of human activities, the number of people with disabilities will increase each year. That is an absolute given.

Therefore if we, as a society, continue to chose to value life over death no matter what the quality of that life or the impact that life has on finite resources, then we, as a society, have to put our dollars where our mouth is. Otherwise, the hypocrisy is overwhelming.

The services currently available to people with a disability such as Marcel Burmester, and my son, are few and extremely difficult to access.

Here's an example. My son's attendance at the School Holiday Program he has used for the past seven years has been cut by 9/10ths in the last six months.

This Home and Community Care program is supposed to "ensure that the consumer's access to a service is decided only on the basis of need", and "to provide flexible, timely services that respond to the needs of consumers". (HACC Guidelines, Service Provider Responsibilities).

However, the carers of young people with a disability who want to secure some days of care at this School Holiday Program must engage in a race. On a certain nominated day you must get your application form in to a certain location where it is time and date stamped.

If I am two minutes faster than you, I get priority. If your need is greater than mine - too bad. I win and you lose.

Is this better or worse than allocating funding on the competitive misery model? Is it an equitable way to allocate resources? Is it dignified for the carers to have to engage in this race?

Does it show respect for the families? Why do all the people I have discussed this with, from the Youth Co-Ordinator of the program to the HACC director in the ACT, think that this is OK? Are we grateful nevertheless? You bet we are.

Chuck us the crumbs and we will sit up and beg for more. It's how we have been trained: to expect little and accept less.

Desperation ensures that we play the game by the rules no matter how unfair or demeaning. But the rules have to change, funding has to be increased and both society and Government have to take responsibility for the less able humans who live amongst us.

Sally Richards, Yarralumla