



# DADAA – Place of Disability in Arts, Health and Wellbeing

## Developing an advocacy strategy

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**Gareth Wreford, Director of DADAA National Network looks at some key issues and discussions around arts, disability and health.**

'Is there a gene responsible for our obsession with perfection?' (Back to Back)

Europe. Also in 2003 Patricia Piccinini's *We Are Family* explored medical intervention in human life and the value of difference through an exhibition of engineered 'life forms'. These polymer and paint figures were presented as ordinary beings with impulses to love and play at the Venice Biennale. Meanwhile back home a much talked about article 'less is more' examined the motivations and implications for freedom of speech and expression of people without disabilities who like to alter themselves to look or feel better. (Tressider)

For the DADAA National Network (Disability in the Arts, Disadvantage in the Arts, Australia) these works highlight some of the issues we face in looking at arts, health and wellbeing. In between preparing an arts and disability calendar for Family and Community Services and maintaining a common agenda between the seven diverse State arts and disability bodies that make up DADAA's core network, an opportunity to sit on my couch and consider why we do the advocacy work we do was welcome.

The notion of 'wellness' inherent in wellbeing has a parallel in our understanding of disability as a socially created problem. The resulting focus on universal access avoids deficit labelling and allows for the inclusion of people who do not identify as having a disability. Recent work by the World Health Organisation (WHO) also seeks to erase the perception of disability as simply equating with illness (WHO 2002).

So should we then advocate for the arts because they make people feel better, should art have a social purpose? This is not a new discussion and was usefully captured at the 2000 Regional Arts Australia (RAA) Esperance conference in two presentations by Chris Sidoti and Margaret Seares, then Human Rights Commissioner and Chair of the Australia Council respectively. Sidoti reminded delegates that the arts 'are both means to worthy ends, such as good health, good education and good communities and ends in themselves ... there is a right to culture, to enjoy and participate in the arts'.

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inner of The Age 2002 Critics Award for Creative Excellence *Soft* is a work developed by Back to Back Theatre in Geelong which explored the social implications of developing genetic technologies. The ethical dilemmas of pre-natal screening and the value of diversity of human form become confronting questions when presented by three performers with Down Syndrome. In 2003 *Soft* has been touring art festivals in



Left-right: scenes from Back to Back Theatre's production of *Soft*. Photos: Jeff Busby.  
Top right: Sally Miller and Andrew Nixon in *in the blood* by Restless Dance Company. Photo: David Wilson.

Citing recent European policy debates Seares stated, 'the claim that artists are different, unique, and should not be expected to explain themselves or why they believe the state should support them will not wash in this day and age'.

In deliberately putting a foot in both the disability/health and arts camps DADAA plays a delicate balancing act. In discussing who should bear the cost of funding work with both artistic and health outcomes 'there is real risk of the activity being supported neither through arts programs nor through health programs' (Walsh). For DADAA members, as with most arts organisations, approaching different funding sources can mean changing the language and highlighting different aspects of our projects to 'fit' the funder.

DADAA National's core support from the Policy Communication Research arm of the Australia Council is recognition that people with disabilities participate in the arts as audiences, and professional artists, across art forms and in community settings. Artists with disabilities don't necessarily see themselves as ill and the diversity of their practice is not automatically the responsibility of the Community Cultural Development Board (CCDB) or a health/disability agency.

DADAA's recently completed Disability Action Plan says we place ourselves firmly within a 'wellbeing' framework because of its currency within our Australian arts and health context. Direct participation in and increased access to the arts contributes to the wellbeing of people with a disability, their carers, family, friends and community. This may be the moment to take a deep breathe, pause and ask yes but what is wellbeing? Like social capital it's used with some abandon and any two arts projects claiming to build social capital and wellbeing may not be comparable.

One of the best local articulations of wellbeing I've seen is in *Just Vibrant and Sustainable Communities – a framework for progressing and measuring community wellbeing* written by Jenny Wills for the Local Government Community Services Association of Australia in 2001.

Community wellbeing 'builds on a social view of health with interrelated social, cultural, economic and environmental factors' (Wills). The World Health Organisation in 1998 identified ten social determinants of health and the international evidence on associated ill health risks (WHO). The determinants include unemployment, transport and social exclusion. VicHealth have pulled together a similar collection of research (VicHealth). Rather than arguing for greater inclusion in the arts because of its health benefits the arts are positioned as part of a broader social inclusion strategy which will have associated wellbeing outcomes. It's an important distinction.



Patricia Piccinini, *The Young Family* 2002. Silicon, polyurethane, leather, human hair. Photo: Graham Baring

For people with disabilities in Australia we know their level of employment is below the OECD average (despite research showing people with disabilities are good employees), access to Education and Training is low and attendance at arts events is below average. The societal context for this debate is Australian Bureau of Statistics (ABS) figures indicating that 18 per cent of the Australian population, or more than three million people, have one or more disabilities. This figure is increasing, in particular with the ageing of our population.

As a Network we start locally and then look to International arts and health strategies – in particular the work being done in the UK.

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Awakenings Roberts Place, Awakenings Festival 2003. Photo: Melissa Pouliot

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The more interesting research I've seen is 'based on an evaluation of arts projects not in terms of reported direct improvements to physical health, but in terms of the factors which precipitate or facilitate such improvements' (HEA). The evidence for such improvements included broad social capital indicators alongside evidence that the social capital outcomes were 'heavily dependent on the quality of the finished product or performance as well as the engagement of the process' (HEA). Heartening words! The same study identified the importance of community 'space' in supporting social capital outcomes (HEA). This conclusion has also been reached in New Zealand where 'Creative Spaces', community places where people can meet and make art, are an accepted and successful model of working with and supporting social capital and wellbeing. The outcomes captured through evaluation are so often limited by the questions asked.

One of the most widely quoted and influential studies in the UK is Matarasso's *Use or Ornament – The Social Impact of Participation in the Arts 1997*. Despite its methodological shortcomings (Merli), the study was timely in coinciding with the

election of the Blair government and effective in the way that earlier English publications hadn't been.

Matarasso's study is, I suspect, much quoted by supporters of the participatory arts because other reports noted a lack of robust evidence supporting the anecdotal claims 'despite many examples of organisations and projects working to combat social exclusion' and the 'fact that this type of work has been subject to more evaluation than any other work in the [arts] sector' (Jermyn and Belfiore).

Interestingly Diedre Williams' 1996 Australian study *Creating Social Capital* influenced the methodology Matarasso used (Merli). Williams' work is for me stronger in its longitudinal focus which is extremely rare (even unique?).

Most international and domestic literature focuses on the participatory arts in a community setting, when examining social impact/health outcomes. For DADAA our interest in wellbeing, following the WHO social determinants of health, ICF and our preference for the social model of disability, has broader components like:

- Social connectedness – friendships, trust, social capital built through access to and participation in the arts.
- Attitudes towards people with disabilities – media, employers, carers, front of house staff.
- Economic participation – access to work, education, accommodation and money.
- Physical environment – design of spaces, equipment, ecological health.

For DADAA building social capital through the arts includes Arts Access (VIC) working with the 2003 Melbourne International Arts Festival and Deaf community to provide a record number of Auslan sign-interpreted events and a marketing strategy building awareness of the accessible aspects of the Festival for people with disabilities.

Also the assumption that art for people with disabilities always takes place in a community setting can itself be discriminatory. Mwerre Anthurre (Bindi Centa Arts) is part of a supported employment service in Alice Springs that is accessed by and services remote communities twice weekly. The Centa is a professional arts development model. Travelling through the Northern Territory in September I saw works from Bindi featured in both Desert Mob in Alice

Springs and the Telstra awards in Darwin. Mwerre Anthure is an artists collective which focuses on promoting culturally relevant work options, expression and arts skill development for a number of Indigenous employees who display a genuine interest in arts career development. The pride associated with a work being professionally exhibited and sold (i.e. productive activity generating an income) can have a major impact on wellbeing!

Generally, for artists who identify as having a disability about 20 per cent say that their disability impacts on their artistic practice most of the time or all of the time while another 20 per cent say it has no effect at all (Throsby).

Our approach to advocacy might highlight the sound public policy reasons to support greater access to and participation in the arts by people with disabilities in addition to the provisions of the Disability Discrimination Act. We might recognise that wellbeing is easier to 'sell' to some non-arts stakeholders than a rights-based argument. Though this is still a two step argument – apart from any cost and health benefits – people with disabilities have the right not to be discriminated against in accessing training and employment and then choose the arts as a career.

We might express a preference for consistent messages that are jargon free and can work across sectors and government. An example of this is the NICAN postcard 'Please consider' describing the characteristics of people who participate in their communities through sport, recreation, tourism and the arts. Access to, and inclusion in, all of them creates an environment which contributes to social capital and health outcomes!

At the risk of 'pulling the wings off the butterfly to find out how it works' the wish list of robust research, relevant to people with disabilities, that we would be interested in seeing might include:

- Comparative studies of arts and other forms of intervention.
- Longitudinal studies.
- Analysis of disincentives and opportunities within the welfare and taxation framework.
- Research which looks for any negative impacts associated with access to and participation in the arts alongside evidence that short term project funding can produce outcomes which transfer into organisational change.
- Better designed research methodologies with control groups, initial analysis of participants' wellbeing.

- Scoping of the outcomes required by different government departments and existing evidence of government departments working together.
- Economic impacts including measures of prevention and cost saving.
- Potential for different arts experiences to build social capital – participatory (both as creators and/or re-creators of others' work) and arts audiences.

At a National level DADAA could be bolder in our advocacy utilising what we already know. Collecting all the evidence in the world won't matter unless we can influence the decision makers who control the dollars!

There are also risks associated with trying to do too much and 'proving' everything that the arts can do – comprehensiveness can be the enemy of effectiveness. DADAA's brief is broad and our resources limited so trying to do the perfect research study or influence 'the government' could take up years of our time and achieve little for people with disabilities. In 'mainstreaming' the experience of disability through a broad focus on health we need to be realistic about what we can deliver and prioritise by identifying and addressing gaps in service provision, program delivery and innovation.

The UK Health Education Authority report 'Social Capital for Health' identified some resistance to evaluation, particularly according to health criteria, that might set uncomfortable precedents for justifying art in terms of its social usefulness. Similarly developing a national advocacy strategy can carry the implication that 'one size fits all'. This is a real danger when what research there is into the 'nature and value of best practice in arts projects which impact health and wellbeing' indicates they are:

- specific, in that there is no one 'winning formula'
- local, in that they tend to be defined and determined by local conditions and outcomes
- generated by personal and passionate impetus (HEA).

Please consider

Characteristics experienced by people who are not members of a community	Characteristics arising from community participation through leisure
Separateness from the real world	Belonging to and being part of communities
Constant boredom	Adventure and challenge
Loneliness	Companionship, increased social networks, new and stronger friendships
Dependence or total isolation	Interdependence
Restricted freedom	Freedom
Bring controlled	Control and power over lifestyle
Limited growth and new challenges	Improved self image through achievement
No sense of a future	Hope and enthusiasm for a future
Feelings of failure	Achievement

NICAN postcard image courtesy of NICAN Inc

This may go some way towards explaining the perceived lack of 'robust evidence'. It may be unreasonable to expect a repeatable model with common and repeatable outcomes that can be easily measured.

The role then of DADAA as a non government organisation in mediating the space between 'the government' and 'people with disabilities' (neither group is a homogenous whole!) in arts, health and wellbeing is worth considering. For all the social capital and community building terms being used within government they cannot create community or build social capital. 'At best they can create policy environments which assist individuals and institutions in civil society to do these things, or at least, do not stifle their efforts or make their task more difficult.' (Hughes). This is an argument in support of Government and community working together! Smarter advocacy which doesn't assume 'the government should' be delivering all services might unlock greater resources for people with disabilities to achieve their goals and aspirations.

Further, focusing too heavily on the social aspects of art produced through government subsidy could limit artistic expression by reducing the arts to a utilitarian function. If diverse forms of cultural expression are not valued generally then it may be more difficult to justify them for people with disabilities. This might then lend support to the arts sector looking at support for people with disabilities in the arts as an indicator of the overall health of the arts sector. More than one commentator has used words to the effect that the measure of a civil society is how we treat those on the margins.

As Jermyn notes:

... currently the focus of policy and research interest is on the value of the arts in reaching non-arts social inclusion goals like health but perhaps there is an argument for saying that arts inclusion should be considered one of the dimensions of social inclusion itself. (Jermyn) This statement sits comfortably with DADAA.

In accessing non-arts resources to support cultural participation by people with disabilities, the language of wellbeing may prove useful in building bridges between some government policy and program silos. The challenge is to do this in a way which broadens rather than constrains the cultural choices of people with disabilities. For DADAA strength through diversity allows room for freedom of expression, experimentation and occasionally getting it wrong!

If Piccinini's 'life forms' were flesh and blood would they be loved? ■



Awakenings Festival 2002 In the Arts There is Only Ability, Dr Coppelia's Toys.  
Photo: Jane Murray

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