

## National Arts & Disability Strategy Input

Marion Conrow - November 2018 – [redacted]

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Hello NADS!

I would like to input to this Strategy as a regionally based interdisciplinary artist who sustained Mild Traumatic Brain injury in 2007.

For those with MTBI there are many issues, its the day before this is due, so the only way I can get this done is just to rant/write. With no carer and one needs NDIS to apply for NDIS, really don't know where to get help for that, but as I seem functional (though those windows are very limited) it probably will be unsuccessful. So starting with about writing this, whilst 12 weeks may seem like a reasonable time frame for those of us without help and executive function issues it is NOT enough time, the meeting in Lismore while was nice it was impossible to answer all those questions in a ridiculously short time frame, the most articulate will have their voice, it will not have the broader picture. Before my injury I worked with policy development and this survey is very important.

For myself and many others, while doing project work, life duties goes out the window, with only 8 functional hours 4/5 days a week, there is basic life stuff like showering dressing eating, but often shopping bills and life admin and chores go on hold and then there is a backlog to attend too. To survive, manage, TIME is key, with limited windows I have to pick my aims, this last 6 months it has been:

1. Creating a new body of work for my first big solo show in Gunnedah made possible with OZCO funding with a grant secured in May, that exhibition has just been packed up and I got home Thursday November 29th to Lismore.
2. My home in South Lismore is flood damaged (cyclone Debbie), finally disaster welfare is assisting to fix my home, but it meant a lot of work, (huge application,(mine was the last cab off the rank), including demolishing two rooms below by myself which is nearly done so work can start next week yay.

This is my first window to be able to take those projects out of my head and now think of this survey, which as an artist prior to sustaining a disability and now re-entering my profession, I have something to offer with my new view into disability. Looking at questions given to us at the meeting in Lismore two weeks would be needed to answer all those questions, there is a book in that, even briefly by the time I answered one lot I would be too tired to continue until the next day dues to executive function limitations:

### Barriers

- if I am having a good day or not, whilst I can “manage”, a bad day means I cannot function attend etc, this makes planning hard, often days are sacrificed prior to resting alone to cope. This in itself has a range of issues and is why when dates are changed suddenly, that can rob a couple of days put into preparation. Projects that are done over a longer period of time with flexible windows and environments are helpful. Ie being in a room with 5 others under fluoro lights is not conducive to many and please remember there are 1000's of people with disabilities locked away at home that can't actually leave the house due to mental issues.. its taken me 9 years to go out in the day to events, night was always easier.. less cognitive distractions..

- Loud noises, bright lights, lots of people talking at once, repetitive noises, background music make attending and participating difficult.
- Finances are always a problem for artists in general. As I write i'm fearful I won't finish as my mac charger has died finally and don't have \$120 to buy a new one. This is being finished this on a PC out of my comfort zone.
- Attitudes, as I seem look normal when I act weird then people in the industry can often hold onto this rather than think oh that's just a symptom and get over it. This can affect employment exhibition and a whole range of opportunities. There is so much stigma with mental health especially if you are on your own with no carer, we can be seen as difficult I am assuming? Lately since receiving the grant and as I am able to cope with more, time has seen these attitudes changing and there is more support.
- Industry, while just re-entering the big world and my experience with disability bodies and services is limited as there is nothing for head injury beside North Coast Brain Injury Service and they are brilliant, but after rehab there is NOTHING for many of us, we are left to survive alone and really alone as most lose their friends family and carers don't seem to come to us nor any other services, we are the invisible, invisible disability people. But I can see that service industries are businesses often for profit and I would like to see more **disability led** services, we also deserve to earn an income and having input like this is crucial.
- Another key point is contact, whilst I was in early stages of MTBI making phone calls was near impossible, so working up to make a call for help often took days and to finally make the call and be treated rudely, dismissed or fobbed off is enough to deter one, (deleted) even with help once to make calls for an advocate, those calls were NEVER returned:(So even if there is help accessing it is very difficult.
- Travel, travelling can be expensive and group transport due to noise, anxiety is a real barrier.

The meeting in Lismore showed me a lot, while everyone meant well and were very nice, the room was echoey, time was ultra limited, I was tired and couldn't cope and left.. all that remained were workers with clients, now did the clients get there say or did the workers? In such an environment it would be hard to get the answers from everyone needed and I am concerned that the voices mostly heard are from abled, there are enough of us with disability that are articulate but i worry for those who aren't and also in my case am only able to engage in such things like this now, where as the early days of my injury participating would not be an option, except for facebook which has helped me no end.

Fortunately prior to my accident with an active arts career where I was just getting somewhere, my CV is good, post accident injury forced to stop, now am picking up and have the mentioned grant and it has a mentorship component. My mentor helped write the grant, it is a great project but that help was crucial to me getting it in! I didn't have that help to go for state funding AND write the grant in the time frame needed, the biggest hurdle was asking for letters of support AGAIN, I just didn't want to hassle again and everyone had helped me so much already. Now i'm in a good starting point but where do I go from here? I need more time to do things than others, my brain is a smart computer with a slow processor and tiny memory, getting able bodied people to get this is hard, i'm not lazy or disinterested, just trying to survive and create! Also second guessing myself so confidence is tricky enhanced by disability.

Often I DO say what my requirements are I.e. needing written information, cant just drop in as planning ahead is necessary. Some get it but many don't.

There are other issues for us with disability including bullying, people taking advantage.

## Outcomes

- **Disability led** service, written and carried out by those with disability,
- **An easy one off starting contact point**, with options, written, facebook, phone, etc with real people on the other end who are TRAINED, every call is important, that call may have taken someone two weeks to make so being fobbed off is CRUSHING! Facebook for many of us is an easy contact point too.
- please include mental disability with equal weight.
- **Allow more time, having this done by March may not be practical, a first draft to be amended over the years? Rather than a total re work, how about revisiting and incorporating feedback. A living document.**
- While the arts is great for expression and voluntary experience we need to not undermine paid artist work with volunteering. Artists work so much for free its important that artist are paid!
- Assistance provided in grant writing, even if fine tuning budgets etc
- projects be disability artist led, vs abled making projects for disabled.
- Clarify the role of volunteer versus professional artists
- flexibility in timeframes and venues, accessibility can be different for many, having a quiet space to have timeout, rest I think is a great idea.
- Paid employment with flexible hours.
- Finance more funding directly to Artists with disability, we do not want a Job network approach where organisation are working at a profit for their own advantage.
- Exposure! Having help to navigate an intimidating sector

An observation is when an organisation supports an artist, turns them into a project then that project succeeds and there is an office and team behind that, it would be great if more artist were so supported. I don't need a lot of support but Arts Management for artists with disability who are professional would be awesome, having to do everything alone is too much plus trying to survive on a low income with financial stress, while having the grant and I am very excited and grateful, but in essence am still working voluntarily for most of the time( ahh the life of an artist why didn't I want to be a dentist?)

Another thing noticed recently whilst exhibiting and attending conferences, is that mostly everyone else in the room, is being paid, I am often one of a minority not on an income. I would like to be paid as well for work contributed.

Arts for people as therapy is brilliant and gives life meaning, expression is conducive to healing, but we need to keep a place for artist professionals, give them paid by the hour work! If this strategy can implement work that is flexible in time for artist with disabilities to mentor teach, practice, that would be fabo. We do work we just don't get paid!

I have loads more to comment and say, the hand out at Lismore was a great selection of questions, I was hoping to answer them all, but time is running out and so is my brain.

Please feel free to contact me, written is a great format for me so I can review in my own time. My turn around time *can* be quick if nothing else goes wrong in my life!! Thanks for listening and i'm sorry for the casual format of this submission, I can do proper work but better to have say than not !!

Cheers Marion Conrow