

## SUBMISSION TO HUMAN RIGHTS COMMISSION ON ISSUE OF AUSTRALIAN DISABILITY ENTERPRISES

I write representing my son, Daniel Shields, aged 38, who is a person with a severe intellectual disability and who cannot speak for himself. Daniel has worked in an ADE for twenty years. His work is the most important thing in his life. He values it immensely and takes pride in his achievements. He springs out of bed in the mornings, he has to be told to stop working and have morning tea and lunch. He comes home dirty, hungry and totally satisfied with his days work. He works at Bedford, Silverwater, which is one of Australia's foremost ADEs and for which I have nothing but praise and admiration. My son and thousands of people like him do not have a rewarding career, a home of their own, a partner or a family of their own. The number of roles that they can assume is limited. However, they can be productive workers and they can be loyal friends. These two roles are played out in the arena of the ADE, where they engage socially with people like themselves and where they are supported to carry out meaningful work.

I strongly believe that the current move to bring about "fair wages" is a front to close down ADEs. I have moved in disability circles in this country for nearly four decades and I have been witness to the ideology that says that any form of specialist service for people with a disability is "congregation, segregation and isolation". This mindset is rampant and vociferous within the paid disability advocacy sector which claims to - but does not - represent people like my son. In fact, it represents no one that I have met in all these years. Couched in emotive terms like "sweatshop" "slave labor" and "exploitation", the argument made by the paid advocates claims that the wages being paid by ADEs are unfair because the assessment tool was unfair. I will agree that the competency component of the BSWAT was unfair but that is a side issue. The big issue here is that funded advocacy agencies are using this issue as a guise to close down ADEs. I know from long experience that they object to ADEs, in the same way as they object to special schools, special classes in normal schools, any form of clustered accommodation, special sporting events, medical services, etc. In opposing an extension of time to design a new assessment tool, they are hoping that ADEs will cease to be viable.

It is important that you understand where these disability advocates are coming from. Many are people with physical disabilities, some of whom were placed at an early age in institutions because their care needs were more than their families could support. They were shut away from society in a manner that would not be sanctioned today. This has led to their great horror of any form of congregation or segregation. However, there is a wide spectrum of disabilities and the experience of these people does not reflect that of people like my son. The call for "inclusion" is often at the expense of the community that my son calls his own. He enjoys being with people who have the same intellectual level as himself and counts those people as his best friends. The ideology that rejects this demeans and diminishes my son's right to mix with whom he wishes and to have his own community within the broader one.

My son and most of his fellow workers could never obtain a position in open employment, regardless of the support that was (most expensively) provided. When he left school, Daniel announced his intention to become a trolley person in the shopping centre. After three weeks, Woolworths told us that they

could not afford to carry enough insurance to protect against the potential damage that Daniel would do (by running into parked cars with the trolleys). So ended his career in open employment. He happily adjusted to his work place with people who are now his friends and has thrived ever since, winning many awards for being the most willing worker and such like. There are so many non-disabled Australians out of work that it is unrealistic to expect people with a severe intellectual disability to be absorbed into the workplace. The fact is that should ADEs close, the great majority of these workers will be sitting at home with nothing to do. And if they are forced to pay a higher wage, most ADEs will close. They are all not-for-profits and they exist on a very fine margin. This I know from my days as board member of one such organization. We had to supplement the losses made by the ADE arm of the NGO by other sections of its business. Finally, we had to close it down because we could not get it to break even. We were definitely not exploiting our workers - we were trying to create a workplace that would give them a purpose in life.

When you hear from the ill-informed crowd from GetUp or the funded disability advocates and their funded lawyers that our people are receiving \$2 per hour, please bear in mind that this is in addition to a very generous Disability Support Pension paid by the Australia Government. My son receives the full DSP, plus rental assistance (he lives at home with me) plus a mobility allowance. Each fortnight, there is more than \$1000 deposited into his bank account through these benefits. His \$75 per week wage from his ADE is in addition to this. Were he to earn any more than this, it would impact upon his pension. For each extra dollar earned, his pension would reduce by fifty cents per dollar. In addition to this, for those living in social housing - and under the NDIS, we are told they will all be living in social housing - all income is assessed and 25% is taken in addition to the rental subsidy. This means that potentially, of each extra dollar earned, the ADE workers will lose 50cents in their pension and 25cents in increased rental. They stand to lose their jobs for the sake of an extra 25cents in the dollar. Our people need their employment far more than they need a pay increase.

I wish to reiterate that the loud voices that are heard in this debate do not speak for me, for my son or for anyone that I have ever met on this long journey through the disability landscape of Australia. The great omission in this landscape is that there is no representation for families like mine. We are the ones who bear the brunt of the care given freely and willingly (though not quite so willingly as we now approach our seventies) and we are the ones who will be affected most if ADEs are forced to close. We have the natural authority to speak on behalf of those most vulnerable Australians who cannot speak for themselves, our sons and daughters, brothers and sisters. And yet we have no funded voice, no peak body, no union and no representation. We are actively excluded from advisory boards, advocacy agencies, think tanks, etc. We are depicted as over-protective and unwilling to "let go". I rail against the power that advocacy groups have in this country and against the messages that they broadcast which so little reflect the lived experience of my son and my whole family.

Finally, I must ask that should the ADEs be forced to pay higher wages and become unviable, then governments must be made aware of the consequences of their enforced closure. There will be thousands of older parents like myself who will not be able to continue to care. There will be thousands of younger parents who depend upon the ADEs to enable their own employment suddenly forced to leave work. There will be service providers across the country demanding extra funding for day

programs or for accommodation services which now close during the day. But most of all, there will be tens of thousands of bored, restless, dissatisfied people with intellectual disability wondering what happened to their jobs and how to fill their time. We must prevent this at all costs - it would be a travesty and a violation of their human rights. If ADEs must pay higher wages, the workers will lose some of their DSP. This saving for government must be immediately channeled back into ADEs to keep them viable. Through this circuitous route we may achieve the status quo - it would be easier to leave things as they are.

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