

Victorian Ombudsman
Level 1, North Tower
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Via email
disability@ombudsman.vic.gov.au

14 February 2014

Dear Ms. Glass,

We thank you for the opportunity to provide a submission to the inquiry into the reporting of abuse in the provision of services to people with a disability.

About Inclusion Melbourne

Inclusion Melbourne is a community support organisation that provides services to people with an intellectual disability, helping them to create more enjoyable and rewarding lives and participate fully in the community. Inclusion Melbourne was established in 1950 and remains the only registered disability support provider to have transformed its services during the life of the previous Victorian State Disability Plan (2002-2012), resulting in the sale of our premises and the delivery of all of our supports within the community, alongside community members.

Our vision at Inclusion Melbourne is for people with intellectual disability to live in an inclusive community, where everyone has the same opportunities to participate in community life and to take their place in society as respected citizens.

We believe our role as a disability support provider is to encourage and enable people with disability to achieve and maintain a valued quality of life. We accomplish this by supporting people to create highly personalised and flexible lifestyles based on their needs and desires. To accomplish this we encourage people to participate in activities and develop relationships with people within their local community.

our response

Inclusion Melbourne welcomes the opportunity to provide a submission to this inquiry. As a funded service provider with over sixty years of experience in the provision of support to people with intellectual disability we welcome the opportunity to assist your investigations into the reporting of abuse as it pertains to Victorians with a disability.

The abuse and scandal that has been reported in the media has been perceived as having an 'upside' - an opportunity to focus attention on things that needed changing in the disability support sector. Sadly that has not occurred. The policy priority around citizenship and inclusion described in the Victorian State Disability Plan has not gained any momentum, even with the recent Inquiry into the Social Inclusion of Victorians with a Disability. Increasingly, the needs of people with intellectual disability are not seen as a priority by policy makers who continue to develop broad policy positions without considering the particular needs of people with intellectual disability, the largest and most expensive group of people receiving funded supports. The outcomes of this approach are clear to see; a website to check eligibility for the National Disability Insurance Scheme - yet research shows that while growing, only 10.5% of people with an intellectual disability use the internet¹.

¹ McCarron, M. et al. Advancing years, Different challenges: Wave 2 IDS-TILDA: findings on the ageing of people with an intellectual disability: an intellectual disability supplement to the Irish Longitudinal Study on Ageing, 2014. Dublin: Trinity College Dublin.



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Ever since the abuse first became public knowledge, the rhetoric around the necessity to act has dominated the disability support agenda. Put simply, the intellectual disability agenda has become only about responding to the immediate challenges that have arisen from the reported abuses. However, concurrently, other negative factors have been impacting on the lives of people with an intellectual disability and their families, including:

- The voice of people with an intellectual disability is being weakened with funding for advocacy cut by the Commonwealth government
- Employment supports are increasingly out of the reach of people with an intellectual disability
- The continued drift towards group living settings because they are incorrectly perceived as being cheaper – despite evidence that congregate living creates long term dependencies and thus expenditure
- The skillset of support staff is being degraded through the financial necessity of organisations seeking to manage the reduced unit cost funding from the NDIS, without reference to the medium and longer term costs arising from a lack of particular expertise in engagement, active support, communication and supporting inclusion.

There is a serious danger that responding to Yooralla will not be a catalyst to positive change for people with intellectual disability. A decade ago there was a growing interest in the rights of people with an intellectual disability, whereas currently the only response is centred on responding to abuse. It is essential to address that agenda, but in doing so we must not forget about the wider population of people with an intellectual disability and whether, as a society, we are valuing them as people rather than slowly slipping back into a pre-1990s mindset of seeing them as a dependent 'group' for whom we need do no more than provide basic custodial care. Without a broad focus on intellectual disability beyond a response to Yooralla, we narrow the framework which seriously impacts on how our society and community works to create a better future for all people.

Choice

Choice is the first casualty of institutionalisation. The nearly 6,000 adults with an intellectual disability who live in supported group homes in Victoria lack many choices that you and I take for granted. They don't choose where they live, who they live with, what they do every day, who supports them, and probably not even when they eat. Even in the best services, it's all about the group, and what's 'manageable' within the resources, leading to a residential living experience that more resembles living in a staff workplace, rather than living in their own home.

So you may live, for example, in a group house with people you would not choose to live with. Imagine if you will, having to do that. Even if you do have activities, they will generally not be activities tailored to suit your particular interests. You will get on a minibus with other residents and go and do whatever it has been deemed you will do as entertainment or diversion that day, if indeed there is any activity planned for that day. One person supported by Inclusion Melbourne has lived experience of this – he used to have to go to a regular dance event for people with a disability but wait outside in the bus for the others because he did not have the \$5 to go in. This is the shallow end of the abuse and dehumanisation of people with an intellectual disability.

The unwillingness or inability to ensure choice – at one or all of the levels (pervasive, lifestyle and everyday) is the benign face of an approach that assumes 'they are not people in the sense that the rest of us are; they are a problem to be managed and they should be grateful to go anywhere or to have a roof over their heads. And the staff do their best.' The stories of abuse, altogether shocking and inexcusable, have grown from a widespread prevailing culture in which people with intellectual disabilities are not regarded as full people. Societal attitudes lie somewhere between conflicting but harmful generalisations. Common among these attitudes are that people with intellectual disability are:

- regarded as children; or
- regarded as being "a pity" - charity cases who should be grateful for whatever we do for them; or
- regarded as people who do not have any desires in life, people who do not have the same wants and needs as the rest of us; or

Attitudes

We remain hopeful of the continued enlightenment of society, and we accept that there are reasons why people have these simplistic views of those with intellectual disabilities. Most people probably do not know someone with an intellectual disability, or don't know them well. Therefore, they tend to have stereotypes, the worst one being that someone with an intellectual disability is less of a person than the rest of us. Culturally, people with intellectual disabilities have always tended to be 'other'. They have tended to live in a parallel universe of institutions and charity, dependent on good deeds. These impressions lead to assumptions and predictions being made about the potential and therefore worth of the person, which have become consciously and unconsciously reflected in the present service system design and therefore reinforced in practice.

People with an intellectual disability do have different and additional needs, and some may not be capable of living the same kind of life as the majority of the population. This however does not mean that we as a society must accept that difference equates with inferior. Fulfilling lives come in many different guises. We must safeguard so that our society does not fall into the trap of assuming that if someone cannot have a fulfilling life in the same way as us, then they cannot have a fulfilling life. For if we don't, we allow beliefs such as 'they might as well sit in the chair all day – they're no good for anything else – they're just a burden on the taxpayer'. Inclusion Melbourne was gobsmacked two years ago when a service provider had the audacity to suggest that they had plenty of opportunities for an individual with a disability, because a spot had opened up on the minibus. It is precisely because these attitudes exist in society that these abuses have been able to be perpetrated for so long.

It is reasonable that every Victorian can aspire (and expect) to be treated as a human being and to progress on their journey through life with education, stimulation and hopefully love, friendship and companionship, all the while striving for personal fulfilment. People should be acknowledged when they reach out for human contact, and to have the humanity we all share in common acknowledged and validated. Recognising the overwhelming sameness of needs amongst us as people, rather than focussing on the few differences is a fundamental safeguard in reducing abuse.

Abuse

Abuse occurs through both omission and commission, and while the acts of commission have led to this inquiry, it is the omission that is potentially the greater evil; affecting many more lives and never being reported upon. These acts of omission include people who have attended centres for decades with little or no outcomes, being contained to prevent escalation of behaviours, behaviours which serve as the only form of functional communication and a clear expression of a dislike for the situation and environment, or perhaps the worst, just being ignored.

The following pages detail five case studies. Each of these real situations occurred in the past five years. In each example there are staff employed who are 'doing the right thing' but in each example, we see entrenched systemic abuse. The common links between these examples are:

- the failure of the system to support beyond programmatic responses;
- the failure of the system to effectively provide early intervention;
- the invisibility of the basic rights of people with intellectual disability and the failure of staff to recognise this
- that abuse of people with intellectual disability takes on many invidious forms, not just those that result in criminal prosecutions

Case Study 1: Miss S: Punishing the victim

Miss S joined Inclusion Melbourne in 2012. At that time she was 53 years old, and had a preference for engaging in community activities. Inclusion Melbourne supported her using a home to community model. By converting a block funded centre based day placement of 18 hours into individualised 1:1 hours, she was able to participate in the community because she was living in a group home that had staffing during the day, so she wasn't forced to be out of the house between 9am and 3pm on weekdays. However, there was a co-resident who assaulted her on multiple occasions, including at times being reported to the Police with significant bruising to her face following assaults. The situation was addressed by removing Miss S from her own home and relocating her to another residential service. Miss S was moved rather than the assailant as there was greater funding at the original house, which was felt would better support the assailant.

In moving Miss S, she was punished for being a victim of assault. She was removed from her home, her support workers and her community, and given the lower level of staffing resources available in the new home, she was required to change her day support provider as she was no longer able to remain at home during the day and utilise the home to community model that she preferred.

Abuses incurred:

- Physical and psychological injury
- Prolonged period of duress while waiting for a response and fear of returning home facing the potential of further assault
- Differentiated access to justice in comparison with the reasonable expectations of most other Victorians
- Removal from own home for being a victim of violence
- Forced removal from known and trusted day support workers due to the requirement to change provider following the change of residential setting

Case Study 2: Miss C: Failure to engage deep disadvantage

Inclusion Melbourne was appointed in early 2013 to work with Miss C, who was then aged 19 and has an intellectual disability. At that time Miss C was living in public housing with her mother and three siblings and other transient relatives in the home. DHS was involved with various members of the family. The support package was only provided following appeals by the special school, due to concerns they had regarding her ability to succeed given the significant risk factors and family environment which included suspected drug usage and sexual abuse. Inclusion Melbourne was therefore engaged to support Miss C to attend a local TAFE program to continue her education.

During 2014, the mother passed away and the family faced eviction as no one had the skills to manage the system, let alone doing so at a time of grief. Despite repeated requests Inclusion Melbourne have so far been unsuccessful in gaining additional support for Miss C to be considered as an individual with the opportunity to create her own life path, rather than being connected to her siblings, for whom she is often drafted to care for infants of transient relatives, drawing her away from her studies and a positive future.

Case study 3: Mr B: Financial abuse, possible sexual abuse and a failure to engage deep disadvantage

Inclusion Melbourne commenced work with Mr B when he turned 19 in early 2013. Staff speak of his beautiful manners and of being very polite. He lives in public housing with his parents and some of his ten siblings. Both parents have an intellectual disability and some siblings have been removed from the home. The physical environment is filthy and constantly smelling of cat's urine. Opportunities for Mr B are limited as he requires a level of support that cannot be met on his current support package. Workers involved with Mr B have had to work at the most basic levels to address disadvantage with him, including:

- purchasing bedding, whereas previously he was sleeping on a mattress on the floor;
- provision of education relating to basic personal hygiene;
- attempting to establish clean spaces within the home;
- the inability of the parents to ensure healthy nutrition;

- His inability to invite anyone to the house
- The parental reliance on him to provide 50% of his pension to cover rent and household expenses; our staff supported Mr B to obtain a post office box so that his family can't see his bank statements and therefore pressure him to provide the funds
- His lack of privacy

Mr B faces a vast array of challenges every day – and he must face these with significant deficits in his adaptive and intellectual reasoning. Chief among these issues is that of changing the nature of the relationships with his parents and supporting his ability to move out of home in order to effect change to his life, yet neither he nor others in his family have the skills to deal with this (nor the support package to make it possible). DHS are working with the parents to educate them re: washing clothes and other basic tasks yet there is a lack of a coordinated response to supporting the family as a unit alongside true person centred planning in order to provide pathways for Mr B and each of the siblings.

Given Mr B's issues with hygiene, he does not have any friends. Mr B's reports having only one friend, a shadowy figure that no support person has ever met, and it is thought he may be engaging in unwanted sexual activity with Mr B.

Case study 4: Miss J: Failing to see beyond the immediate crisis

Miss J began to receive supports from Inclusion Melbourne in 2013 at the age of 22. She had a history of challenging behaviours and at the time was living in an SRS in metropolitan Melbourne. Over 18 months Inclusion Melbourne staff were able to positively engage with her and was the first disability support service in over 3 years to not have any staff be assaulted. Miss J values trusted positive relationships above all else, and carries with her trauma of painful periods in her life, one of which was revealed to Inclusion Melbourne when Miss J, in the company of a support staff, noticed a man who she advised was her ex-boyfriend and that he had raped her in 2011. Miss J was angry to see him and became agitated. Staff suggested reporting them matter to police, and Miss J replied that the matter had been reported but that the police 'had done nothing about it'. At that point, Miss J walked up to the man and assaulted him. Passers-by assisted in separating the pair before the police arrived. Miss J then continued walking (to the station) while our staff attempted to calmly address Miss J's anxieties, to no avail; Miss J then ran on the platform towards the train tracks expressing that she wanted to die in front of the approaching train, but was pulled back. Four ticket inspectors who had witnessed the scene then approached Miss J and escorted her off the train, resulting in her hitting one inspector twice. She was then restrained against a fence, during which time she had a seizure, resulting in police and ambulance attendance and transfer to hospital.

Throughout 2014, DHS case management continued searching for supported accommodation for Miss J, resulting in locating accommodation in Morwell. Miss J expressed displeasure at the move, and Inclusion Melbourne attempted to advocate on her behalf, but was viewed as a provider simply seeking to maintain the client's funding.

While meeting the staff member's need to close the case, the placement has failed to acknowledge the trusting relationships built between Miss J and Inclusion Melbourne staff; support to address her unresolved issues relating to prior sexual assault, and dislocated her from family, everyone that she knows and her local community to a foreign regional town. Further placement in the group home was contingent on her attending a local day service, yet her history is clear through her behaviours that she does not like to attend group activities and is able to form bonds with workers working one-on-one.

Case Study 5: Mr K: adopting a crisis based approach to support allocation.

For many years, Inclusion Melbourne worked with Mr K, now aged in his 40s. During that time we partnered alongside Mr K to build a life in the community that included employment. Mr K also had mental health concerns, and Inclusion Melbourne advocated for an increase in his support package to be both reassessed (from SNA 3 to SNA 4); and to be increased from part time to full time supports. Despite numerous applications for support, meetings with the DHS & the family where assurances of action were given, no additional support was provided. Over the course of 2 years, the mental health of Mr K deteriorated and he progressively lost each activity

in the community as the community environments were unwilling to have him attend without paid support due to his anxieties and behaviours. The final response was to move the person to a traditional day centre, stating that he wasn't a candidate for community based supports. This required that his funding be increased as per the initial request made 2 years earlier. Had the request been favourably received at the outset, this man, nor his family, friends and support staff, would have had to endure the mental illness and anguish that he was forced to experience, nor the time and costs and effort required for his recovery.

Our submission suggests that as a part of this inquiry we should challenge the widely held community attitudes as to what we regard as a worthwhile person and a worthwhile life. What has occurred and been reported in the media is a product of a culture in which we live. If this inquiry enables our community to rethink our casual culturally ingrained ideas about who is a human, who is afforded rights and who is supported to access justice, then this will serve as the best way to prevent anything like this from ever happening again.

We thank the Victorian Ombudsman for raising and enquiring into this important matter and for the opportunity to provide input to this work.