Action for More Independence & Dignity in Accommodation

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Advocacy, Self Advocacy, Rights, Accessibility, & Community Living for People with a Disability

AMIDA submission to the Senate Inquiry into Violence, abuse and neglect against people with disability in institutional and residential settings.

Action for More Independence and Dignity in Accommodation (AMIDA) supports people with disability as valued members of our community. AMIDA recognises that people with disability contribute to and develop our community.

AMIDA acknowledges that people with disability have a right to a choice of who they live with and where they live. Further, people with disability have a right to good quality housing which is accessible, affordable and non-institutional. People with disability have a right to live in the community with access to support to participate and have a good quality of life.

AMIDA is an independent advocacy organisation which advocates for good housing for people with disability. We provide advocacy to individuals, with priority given to people with an intellectual disability, and advocate for change in systems which prevent people from achieving good housing.

AMIDA strongly supports the United Nations Convention on the Rights of Persons with a Disability and works to assert these rights and community inclusion for people with a disability

The following is our response to the terms of reference of this Senate Inquiry.

a. **the experiences of people directly or indirectly affected by violence, abuse and neglect perpetrated against people with disability in institutional and residential contexts;**
b. **the impact of violence, abuse and neglect on people with disability, their families, advocates, support persons, current and former staff and Australian society as a whole;**

We have many members and clients with firsthand experience to share. We submit these stories on their behalf. Some have indicated they are happy to use their real names and others have asked we use a pseudonym so their real name is withheld. We have indicated where a pseudonym was used.

Some of the experiences people have had happened recently. Others happened in institutions that have since closed. However institutions remain open in Victoria and across Australia and so this experience is still relevant. In addition, to date, there has been no Government inquiry focussed exclusively on the experience of people with a disability who suffered abuse in institutions and residential settings. This is the first opportunity people have had to be heard by any Government focussed on what has happened to people with disability. Many have been waiting years to tell their stories. While apologies have been made to the Forgotten Australian children who were placed in institutions and to the Stolen Generation of indigenous people, no government has apologised to people with disability for the deprivation, neglect and abuse they were forced to endure in government run and funded institutions, not just in childhood but well into their adult lives. Perhaps this is because institutions still remain in operation across Australia. Large and small, government and non government and even private businesses still congregate and segregate people with a disability. Research has demonstrated this increases the likelihood of abuse. (Sobsey 1994) Australia, in ratifying the Convention on the rights of Persons with a disability, has agreed to end institutional forms of accommodation for people with a disability, and yet they continue. It is well past time for apologies. It is time to close all institutions now as a first step and provide person centred support and accommodation in community settings that does not congregate and segregate people with a disability.

We also urge the committee to view a copy of the Hidden Lives DVD which Jane Rosengrave will present to the hearing in Melbourne on Tuesday 30th June 2015. Hidden Lives is a stART community art project (contact person Sue Smith 03 96396856). Thirty five people who lived in institutions worked with community artists to produce the Hidden Lives exhibition. The exhibition was shown in Collingwood, Warnambool, Frankston and in the former institution in Sunbury. Hidden Lives provided an opportunity for these people with disability to have their stories and experiences publically recognised and acknowledged. The DVD contains the majority of the images, animations and films from the exhibition. AMIDA would like to thank those people who have also recorded their stories in writing in our submission for the committee to learn from.

Terry Neal's story. (Terry's legal name is Terry Stanton but he prefers to be known as Terry Neal)

My mother couldn't look after me. I was first put in babies' homes, Mrs Mintons infant welfare was the first and I passed from there to Box Hill Salvation Army boys home and then Kildonan. I went to from there Kilmany Park boys farm in Sale. After that I was in Tallyho Boys village in Blackburn. From there at 14 I was discharged and went to my Mum and step father for a while but they arranged with children's welfare to have me put in an institution and one day the welfare people came and I was told that I'd be living with them and be looked after. They didn't do that and instead I was driven to Bendigo and put into Sandhurst Centre. I stayed only a few months and I kept running off and I'd be caught and dragged back. I got angry and violent so they put me on psychotropic drugs. In the meanwhile they were making arrangements to have me transferred to Aradale in Ararat.

I played up there and they put me in the intractable ward. I smashed windows and threw chairs and they had me transferred to J ward at Ararat. I was in with the criminally insane and I was only 15. There was a link between J ward and Aradale but they were about 2 miles apart. In these places I got sexually abused by inmates. Staff bashed me. I got bashed so severely in J ward I had to go the Ararat hospital for a week because I was black and blue. Back at Aradale I grabbed one of the orderlies that bashed me and I bashed him. They gave me shock treatment as a form of control after that. I had told them I would come after them if I got out of that place. I went on a hunger strike in J ward. The more they pushed me the more stubborn I got. I was there nearly 2 years.

An old fellow Burt Kitchener came to Aradale as a patient in his 70's. He had been a university lecturer as a youngster and he was committed to Aradale by his family who were after his money he thought. We became good friends. I was only a young fellow and he took me under his wing. He got out first before me but me promised he'd get in touch with my mother to come and get me out and if I couldn't live with her I could go and live with him in Springvale. I didn't hear back for nearly 3 months but then I was in the intractable ward exercise yard and a nurse called out to me and said come with me. I asked why and was told to shut my face and I was taken up to the head office where I had to sit and wait. Then I heard a familiar voice and I listened through the door and it was my mother. The superintendent was pleading with her to leave me there and that I couldn't live in the community. She insisted and I was discharged. I got out but she wouldn't have me live with her. I went to live with Burt in Springvale.

He was a good guy. I lived with him only 6 months and I was out shopping one day and when I got back I saw him on the floor of his bedroom. He was dead. So then the police came and said I had to go home to my parents but I said they wouldn't want me so a social worker, Mrs Begs came to see me and said I would go with her because she had some very nice foster parents who would look after me. I said I could look after myself but they wouldn't let me leave so I had to go in the car with her and she took me to Bundoora-Lurundel psychiatric hospital. I tried to get out when I saw the sign near the front gate but she grabbed me and they took me inside. I was there 6 months and then they made arrangements for me to be transferred. I was placed in Caloola an institution in Sunbury. It was the only option and I was seen as a problem. I was never given a proper education. I was made to work and yet they never let me go out and get a job. The only way to get out was you had to apply to the Superintendent. In the 8 1/2 years I was there I applied almost every week and they never let me out. I was bashed there and had fights with staff and other patients. They said there was no way I could be let out because I would be violent and a danger to society. Yet when I finally did get out I was able to live in the community for the rest of my life without hurting anyone. I was reacting to abuse and deprivation of my human rights and civil liberties.

I got out in 1967 and I've never been back living in the institution since. I actually escaped by taking a staff members key out of the door and I locked him in the linen room and got out. I've still got that key. I keep it on my key ring. I was almost 25 and I'm going on 72 this September. So I've been 47 years in the community as a good citizen and the only time I've been in any trouble with the law was at protests to defend the rights of people with a disability. I was at the Miss Victoria protests and I got arrested as I was standing there holding a placard. Over the years I even protested to have Caloola closed. I've been a big supporter of social causes if I thought they were up my alley. I'm a survivor of torture and I'm in organisations with other survivors. I was psychologically and physically tortured by the state. They were supposed to look after me because my family couldn't look after me.

Large groups of people should not be housed together. It creates institutions. There has to be a better life in the community. When you place people in charge of others they just clock on and don't care. They take their personal problems out on the clients who they have power over and who can't get away.

I was living in Yarra Housing Rooming House in Fitzroy. The place housed 12 men and women. A bully moved in who had just got out of jail and was threatening people and trying to extort money out of people. He was in his 40's and most of us were older. He was making it uncomfortable and it didn't seem like anything was being done about it. I moved out and wouldn't go back. I was there nearly 10 years.

I left there over 2 years ago and I now have my own 1 bedroom Public Housing Place. It's small and poky and not the area where I want to live but it was the only option they would give me. I was homeless after I left the rooming house and sleeping a bit rough so I took it. It's cheap rent and it's safe.

I would recommend the closure of all institutions be they public or private. The private boarding and rooming houses and Supported Residential Services are just as bad. They are mini institutions run by dictators and you have no say and no rights. They don't even have to give you notice. You get kicked out if you speak up. I wouldn't last very long.

What we need is more public housing in the areas people want to live. The rent needs to be really cheap so you can live. Let me tell you money is an issue when you're on a pension. People battle to keep the rent up in private rental.

I would be prepared to talk to the Senate if they would like the benefit of my life's experience.

Terry Neal

Graeme Williams's story

My mother put me into Kew Cottages when I was a boy. I went from place to place until they took me to Caloola, an institution in Sunbury Victoria. They said, "You are here for a holiday". That was not true. I was in a locked ward. I was in institutions for about 30 years.

I got no training. I learned to read and write when I left. All they taught us was how to clean up the ward. We did not get good health care. If you said you had a headache the staff just told you to drink lots of cold water.

It was not safe. One time there was a fight and this guy got his arm broken. He did not get a doctor for a long time because the staff was in another room talking. I was not bashed. Other people I know were. I was not taken into the sheds on the farm. Other people I know were. Everybody was too scared to tell.

It was cold at night, with only one blanket and a pillow. The mattresses were thin. If you did not get up in the morning they threw a bucket of water on you.

Another time staff made lies up about me. When I got up they said, "No breakfast for you." And I was taken to Mont Park Hospital. The Doctor said, "The staff said you'd been talking about killing yourself" I said, "No I never did" but they didn't believe me, and I had shock treatment, five times. They wanted to keep me at Mont Park because I was a good worker and cleaned the wards. I do not know why the staff made up stories about me. Maybe they did not have anything to do.

I ran away from Sunbury, but staff saw me on the highway and the police brought me back. For punishment they stripped me naked in front of everybody in the dinner room. I ran away again, and they put me in a locked ward. Two men from the day shift were going to bash

> me for running away, but a good night shift came on in time to stop them. They had to put on another night nurse for a bit to stop me being bashed. Other people were not so lucky. John (pseudonym) got bashed. They waited till the other staff had taken the residents for a walk and they took him into a single room and bashed him and scared him with a knife not to talk. John had not done anything- he was just weak and could not fight back. They tore Tom’s (pseudonym) clothes off in the meals room, just for fun. I went to the administration and told them they should look at what’s going on in M2. When I got back this staff member told me, “You are a dog, you dobbed me in, get outside, you are not getting a meal.”
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> I had to get out. I asked for day leave. I stayed out for the weekend, and slept at a friend’s house. I rang them and said I had a paper delivery job and I was not coming back. “No,” they said, “you have to come back. You have to see the Doctor.” The Doctor told me, “If you go outside you may get yourself into trouble.” I said, “No, I will not get into trouble”. I wanted to go. He gave me some papers and said, “Sign your name.” And I was out. I did not get any help to leave. I had been in institutions for 30 years. After a while a friend put me onto a social worker and I got some help.
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> Since I have been out of Caloola in Sunbury I have my own friends. I have been able to help people who want my help. I can get good doctors. Nobody tells me to go to bed at nine thirty every night. I can have a shower without a staff member watching me. I can see my friends when I want to. I have my own garden. I have a dog, Rex. I know my neighbourhood and neighbours. I look after their birds if they go into hospital. The old lady next door brings me soup when she makes it. We look after each other. I have friends at the church. I work too. I have been a community visitor at Sunbury. I did well. I knew where to look and who to ask to find out things. I do work for AMIDA. I enjoy my life.

Daisy Serong’s Story

Daisy was born in 1942. When she was two she and her siblings were taken from their mother by her aunts and she was put into the care of the nuns at the Abbotsford Convent. “My mother couldn’t read and write and they didn’t like my stepfather so they took me” she said.

After several moves between orphanages and nunneries, Daisy found herself at Royal Park Hospital for the Insane. In 1960 she was sent to the Sunbury asylum, which became Caloola, in Sunbury. Tragically, at a dance for patients she discovered her brother John, who she had not seen for 30 years, was also a patient. “He looked familiar but I did not realise he was my brother. Nobody told me.” Her sister Ruby, who had been a companion, died at the asylum. She was buried by the state at Sunbury cemetery. “John told the priest to put a white wooden cross there for her otherwise she would have been buried with nothing,” she said. Daisy left Caloola in 1983 after 23 years there and set about “learning my rights”. “People weren’t treated well there and I didn’t feel well there.”

With her brother, Daisy became an advocate for people with an intellectual disability. She lived happily and successfully in the community for the next 27 years until moving into a nursing home. Although she suffered periods of mental ill health she has been supported through this in the community and never required hospitalisation. In the last 5 years both Daisy and her brother John have needed more support as their physical health needs have escalated no doubt in part due to decades of deprivation, neglect and abuse. They both still attend AMIDA meetings when they can and speak up for the rights of people with disability.

Jane Rosengrave’s story (previously named Jane Hauser) - Jane has also verbally told her story to the Royal Commission into Institutional child sexual abuse

Jane's family fell apart when she was a baby. The three older children were all taken to Allambie as undischarged wards. But Jane, who was just six months old, did not go with her siblings. Instead, she taken to the Turana Nursery on a Protection Application and then, the following month, she was admitted to care after the Metropolitan Children's Court 'Unfit Guardianship' decision.

'I was always kept separated from my family because of my fits. I had fever seizures from when I was a little baby of six months. I was sent to the home, because of my fits. I was taken to Nazareth Boys' Home, in Sebastopol.'

Nazareth Boys Home, or St Joseph's as it has also been called in the past, was a big, two-storey bluestone mansion in Grant Street on the outskirts of Ballarat. In 1913 it was purchased by the Roman Catholic Church and, following various building developments, it was soon operating as a Home for Boys. At its peak through the 1950s and 1960s it was staffed by close to 50 workers and catered for around 170 children. It was primarily a home for boys aged between 6 and 14, though it also accommodated some girls under the age of 6, who were then often transferred to a sister institution, Nazareth House in Ballarat. Boys on the other hand, could remain at Nazareth Boys home until they were 16. Jane lived at St Josephs for over five years.

'When we wet the bed I had to lie in the wet bed and miss breakfast as punishment. The nuns or nurses would come in the ward and feel the sheets to see if you have wet the bed. If it was wet they would punish us by putting the sheet over our heads with big safety pins pinned to the pillow. And you'd just lie there to smell your own urine for punishment. And some mornings we would go without brekkie too.'

But by the time she was almost five, Jane, according to one of the staff at Nazareth House, was causing quite a bit of trouble and needed to be placed in a special school. Jane was, 'impossible at kindergarten and most upsetting and even viscous with her companions and a trial to the Staff', wrote Sister Lalane. 'I do hope that you may be able to have Jane transferred to a suitable school' she wrote, 'and soon'.[1] It seems that for a while, Jane would be sent to Nazareth Boys Home in Ballarat, but in May 1968, a report shows that Nazareth Boys Home would not take her for the Social Welfare Department Report, which identifies Jane as Jenny Hauser, was not flattering. Jenny Hauser 'screams and shouts at story time', wrote Mr. Renkin, the Regional Officer, she 'is a problem child, she has been to speech therapy at Dana Street but they could not control her. Demands notice by her behaviour, will eat all day'. In any event, on 27 September 1969, Jane was transferred to Pleasant Creek Training Centre, in Stawell where she would live for the next 21 years.

Pleasant Creek

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[1] File 1 elite, Letter to director of Social Welfare Depart, 24 January 1968.

‘It is a big part of my life’ Jane has said of her time at Pleasant Creek. “I want people to know what happened to me. I want them to learn from what happened to me. So they can realise what not to do in the future, for their people, for their kind of child, to what we’ve been through, that’s why. I want to tell my own story so I can let my friends know what life I have been through.”

‘I’m writing a book. I have the cover worked out already. I’m thinking of a big bird cage with a person in it, like me. I might put a picture of the Institution on the cover as well. It was like a gaol, a cage. When I got out of that place I was free.’

The Pleasant Creek Colony in the town of Stawell was established in 1937, when the former Pleasant Creek Hospital was taken over by the Department of Mental Hygiene. Run along the lines of a 'farm colony' Pleasant Creek accommodated older children and young adults, up to the age of 20. People who are certified and admitted into institutions were stripped of the support provided by social relationships. On admission they were required to adapt and accept a totally different enclosed and alien world. The institution regulated everything. (Potts and Fido 1991, 57) Perhaps Pleasant Creek was not all that different to the sort of institution outlined by Goffman in 1968: ‘The patient’s life is regulated and ordered according to a disciplinarian system developed for the management by a small staff of a large number of involuntary inmates. In the system the attendant is likely to be the key staff person, informing the patient of the privileges and rewards that are to regulate his life and arranging for the medical authority for such privileges and punishments.’ (Goffman, 1968).

Toddler’s Ward

It is certainly a system of punishment, reward and control that comes out in Jane’s story. ‘I can remember going to bed early when we were naughty even for wetting the bed in Toddlers Ward. We sometimes had our noses rubbed in it’. ‘When I was in Pleasant Creek Training Centre in the Toddler’s Ward occasionally we had to go to the toilet and we had three to five minutes to go to the toilet. The other issue is we had to hold ourselves (not allowed to empty the bladder) for an hour or two if we misbehaved. We even had to hold ourselves when we were in the corner kneeling on our hands and knees against the corner or with our hands on our heads and we had to stay there for an hour or two and if we wet ourselves we would get our noses rubbed in it. We used to get a lot of nappy rashes. We never had any cream put on it and had to put up with the pain. I can remember getting my pants pulled down in front of everyone in the dining room and getting “Charley the strap” for wetting my pants and not doing as I was told. I was in the toddlers ward from 1969 to 1972.’

‘Sometimes before we went to school on weekdays and on weekends we had to sit on the wet grass and cold cement for an hour. That happened a lot in toddlers. When I was in toddlers, I used to sleep in the back dormitory with the girls. Some nights we would play Hide and Seek and jump over the beds. If anyone got caught by the night nurse she or he would punish us by taking us up the passage near the office and making us kneel against the wall with our hands on our head for one or two hours.’

‘When my mum died sometime in 1971, I was eight years old at the time when she died. I was told by one of the nurses in the dining room. That’s when I realised there was a family out there that belongs to me. I would not eat my tea that night. One of the nurses took me to the Toddlers Ward to be away from the other children that night. I kept on crying all night. That night, while I was in bed crying, the night nurse told me to “shut up and get to sleep or I would be sent to the office and have to kneel against the wall”. We used to go for our walks on weekends. If we wanted to go the toilet we were told no and had to hold ourselves until we got back home.’

‘The second Sunday in January, every year we would go to Marlborough House, in Portsea, for two weeks for a break from the institution. There were twelve staff and a bus load of children from the home. When we were down at Portsea at night there was always one staff member looking after the children while the other staff went down to the Portsea pub for tea. One night when he was on duty, he asked me to rub his head so I did, then I was starting to get very tired. So I asked if I can go to bed and he said “I will take you up there.”’

‘When I got up there he watched me get undressed then he touched my private part. Then he took me to the toilet and I had to feel his dick and he touched my fanny and boobs. When I was very young I did not know what was right or wrong, because we were not taught properly. When I was back at Pleasant Creek a couple of months later I went up to the boys ward at night. I thought it was normal to do this type of thing.’

‘When we were in the toddlers ward we would line up in the nuddy (naked) in the cold with nothing on ready to have a bath when it was our turn up. If we were naughty or noisy as we were in a line waiting for our turn to have a bath, the nurse would punish us by saying to go at the end of the line.’

‘When I was in the toddler’s ward of Pleasant Creek, May Hall, from the front office, took me to see a doctor at Epworth Hospital about my fits. And she took me back to the orphanage to see the nuns. Then she took me back to the institution. I can remember when I was in toddlers ward if we were naughty we would go in the sick bay and stay for an hour and watch the others play down in the yard on the swings and monkey bars and even swimming. Sometimes if we were naughty that day we would be punished and had to go to bed at five thirty that night.’

Senior Girls Ward

‘When I was at the school there was infants, juniors and seniors. One of the nurses in 1973 and 1974 in the senior girls was cruel. She used to pull people’s hair. A senior girl had a problem with her head and the nurse knew that. She didn’t like to have her head touched and the same nurse used to do it to tease her. When one of the girls got angry one of the staff members would punish her by making her go to bed without dinner.’

‘I can remember a guy from the institution. He did not like water at all. The staff used to duck him when all the wards were down swimming during the weekends and during the week.’

‘When I was in Senior Girls in Pleasant Creek between when I was 10 and 16, one of the nurses would make us girls go down to the TV room because she didn’t want to take us swimming. I asked the other girls if they wanted to go swimming and they wanted to go so I went down to the front office and asked the head nurse who was in charge of all the wards that day if he would ring up the office in Senior Girls and ask the staff if we could go swimming.’

‘He said “first he wanted me to do him a favour”. He said to me to “go to another office and pull my pants down and get myself ready”. He locked the front door then came to the office that I was in then he pulled his pants down and started playing with my fanny and then I had to play with his penis. He had his hankie ready when he came and he said to me not to tell anyone ever or the girls would never go swimming again. He did that to me over a couple of years during the summer when it was swimming time.'

'On a Saturday morning we would go through our dirty clothes in big white bags. On a Friday night the staff would put clean day clothes on our beds and sheets as well for the following week. With the sheets we had to throw one big sheet on the floor and put ten of the sheets on top then we tied them up then the staff would tell us to take them up to the laundry. We used to throw them over our shoulder and walk up to the laundry. They were bloody heavy, we used to get sore shoulders sometimes. We had to carry the bags with the clothes in them.'

'Before we went to school some days in the week, us older girls had to sweep the floor and then mop it and polish it. The staff would have a list of the girls whose turn it was to clean the ward that day. Sometimes if we were naughty and didn't do what we were told we were made to stay back from school and finish the cleaning of the ward. Us girls used to have tons of fights with each other. Nicknames like retard, spastic, mental case. There was one girl who had red hair. We used to call her red head tomato head for her nickname. She hated it. For the ones that had fits like me we would call them fit taker. I did not like it one bit. Some girls would run away from the institution and try to go back home where their families were living. If they got caught by the police they would be returned to Pleasant Creek and that's when they got in serious trouble by the head nurse on duty. They would go without pocket money for that week.'

'I can remember one of the boys ran away from the place. Each time a car or a truck went past on the highway he would hide behind a tree. Then when there was no car he would start walking back to Melbourne. It took him seven days to get Melbourne. He got back home to his parent's and family. Five days later the cops come to his parents place. He told his family everything on what had happened there and did not have to go back to Pleasant Creek.'

My Move to the Hostel

'When I was moved to the hostel I was living in a room on my own. It felt strange being in the bedroom on your own. I was so used to being with the others around me in the wards. I gradually got used to being in a room on my own and I got to like it.'

'When this bus driver used to take us to church on a Sunday he started talking to me. I was only sixteen and he said to me, after he got to know me a bit better, "would I like to go out with the family?" I said "yes" to him. I was happy as it would get me out of the place. He had to get permission and he said he would talk to his family. They got permission so I was allowed to go out with them one day a week on Saturdays or Sundays.'

'He drove the bus. I used to go to put the bus away with him. The bus company was owned by the Sandilands bus company, which is still in the town of Stawell. After about four months the bus driver started to feel my fanny through my clothes then my boobs and later down the track he wanted full sex. He said to me that "if I was ever to tell anyone what was happening at the back of the bus I would never go out with them again." I was forced to have sex with him a lot and this went on for about three years. I was scared and frightened of his temper.'

'Half way through the first year, once his family got to like me a lot, they offered me money to work in their shop on a Friday night and Saturday morning. The hours were from five to nine on a Friday night, and on a Saturday from nine to midday. Then they would take me back to Pleasant Creek. I was allowed to stay on a Friday night. Sometimes he would get his family to go home and I was left with him in the shop. When the shop closed we went down into the basement and he would make me have sex and threaten me not to tell anyone or I would be left in the institution.'

'I would go for walks with him and walk the greyhounds but he didn't do anything. I remember doing the mail and bread delivery run all around the area. The places we used to go to deliver were Jeparit, Minuip, Deep Lead and Dadswells Bridge. Sometimes the family and I would go to Horsham of a night during the week.'

'I would go on holidays with the family for ten days at Christmas time. When it was time to go to Portsea with the other children from Pleasant Creek, I wanted to go with them. I wanted I break from the family so I can be with my friends. I would go to the families place for the whole day. They were first living in Stawell, and then they moved out to Deep Lead after they built their new house. I went out to live with them sometimes for weekends. One of the cooks from Pleasant Creek said that when they slept in the house they made me sleep in the caravan in the cold and that I was not looked after properly. Sometimes when I came back to the hostel from being out with them I would not be happy because I started not to like them. I was scared to tell the staff at the hostel what was going on between the man and me. I was actually frightened and scared of him because of his bad temper he had. The family started not to like me as they thought that he was spoiling me. He spoiled me to get what he wanted. He had a very bad temper and I was scared of him. So were his family.'

'When I turned 21 I went to a rented flat in the town. I liked being on my own, it was good living on my own for the first time. I needed someone to teach me how to cook so one of the staff from Pleasant Creek came and taught me how to cook and how to live on my own, how to make casseroles, how to make cakes and puddings. I used to be out and about a lot, visiting friends. I was on my own because I didn't have a family that I knew of, until later on.'

'I had a job as a domestic cleaner at the hospital. At first I enjoyed the job and the extra money but after five years at the hospital I had had enough. By then I had a gut-full of the hospital because they were giving me hell. Because I was from the institution, I was not from the outside. I was always in trouble there. Because of my fits, I used to sleep in a lot, and I used to get staff coming down to the flat, banging at the windows and that, telling me to get out of bed, go up to the hospital. My partner, Ted, and I had already been looking to move to Melbourne and did in 1990 in November. Ted and I went down to Cranbourne to live, where we lived for 24 years.'

'That was when I didn't know about self advocacy. It would have been probably about three years after I'd been down there, that I got to learn about self advocacy through Westernport Speaking Out because they came up to Cranbourne to the community house. It was Diane I think, or someone. She was teaching us how to be a self advocates, how to stand up for ourselves, what things do we already know about self advocacy, what things did we already know about what was our rights. I didn't know much, because I was from an institution. I got a phone call about a month later, from Westernport Speaking Out. They asked me to come down to their office and if I would like to be on their committee. And I said: "Yes", and that's where my self-advocacy started from.'

'You can do different things like coming up with issues and what to do, you can stand up for yourself, get other people involved, bring up new ideas, try to get more money for advocacy. I go out to Community Residential Units (CRU) and talk to people with disabilities. When you go to CRUs you see that things have not changed. I've seen the staff have still the same ways of treating the clients like from the institution. They do get a chance to go out but don't handle their own money. Some of the CRUs, I don't know about all of them some of the people in CRUs aren't allowed a key and have to be back at a certain time. Things have not changed that much.'

'I want people to know what I have been through. I want them to see how hard my life has been and learn from the mistakes of the past.'

Alex (Pseudonym) lives in a Supported Residential Service (SRS) in Melbourne, after having moved to supported accommodation 3 years ago because of his increasing need for personal support. Alex uses a wheelchair and has an intellectual disability.

Since moving into the SRS he has experienced violence at the hands of fellow residents on a number of occasions. His case manager and advocate have been involved, and have followed up with the SRS managers to ensure that they have followed the correct procedure for reporting these incidents. Police, doctors, DHHS have been informed. Another resident has been issued with a final warning having abused Alex.

There have been instances of verbal bullying, which have been also notified to the SRS managers. Despite all regulations for reporting the abuse having been followed Alex still feels scared and unhappy to be living in an unsafe place.

This abuse has all taken place while Alex awaits the allocation of a funding package for support and/or appropriate supported accommodation. Numerous Disability Support Register reviews and updates have taken place, and the most recent review has resulted in his application being put in the ‘urgent’ category. The support Alex receives is not sufficient to prevent hygiene issues which impacts on his community inclusion. Alex waits for the support he has been approved to be funded. There is no guaranteed limit to this waiting time. There is no guarantee the funding will be enough.

Even if Alex’s support funding increases there is little likelihood of an alternative residential service to the private SRS. Government funded Group homes, funded under the Victorian Disability Act, are in high demand and there are no current plans to expand this stock in Victoria. The government funded Group homes are less institutional, have on average 5 residents, are better regulated with tenant rights and access to VCAT, and are subject to independent quality certification. They also charge a maximum of 75% of income for full service.

The SRS however, is a private business not just meeting costs but making a profit. It provides shelter, meals, laundry and cleaning. Many people like Alex use their own government provided support funding to have agency staff come in and provide their personal care each morning. On average 34 people live in each Victorian SRS and some have as many as 70 people. Residents pay at least their whole disability pension as a fee and in 22% of total cases they pay above the pension. They have no tenancy rights. As of October 2013, there were 143 SRS businesses registered with the DHHS, providing approximately 4930 registered beds; A ratio of 34 people to each SRS. In contrast there are 1000 fully funded government and non government group homes providing 5041 beds; A ratio of 5 people to each group home. The waiting list for a group home place is in the thousands.

This state of affairs leaves Alex vulnerable; his hopes rise, and then are dashed and he is again disappointed. He feels that he will never leave the accommodation where is so unhappy.

The abuse and violence directed at Alex have left him distressed, bruised and hurt. He is very anxious to move to other accommodation, but this has not eventuated. If he did move to other similar SRS accommodation there is no guarantee that the same or similar abuse would not occur. A group home regulated under The Disability Act is smaller and Alex would be more likely to get appropriate support. Alex aspires to this, and it is what he has been approved for. This means that his needs have been recognised, but because of a lack of funding for more appropriate, less institutional accommodation or funding that is directed elsewhere, Alex continues to live in accommodation that is congregated, segregated, and where he is subject to abuse and fear of abuse.

In the case of Alex, the reporting practices appear to have been followed, yet this did not stop the abuse happening again. This abuse was reported to the Victorian Ombudsman, who took down the particulars as part of an investigation they are doing, but were not able, under their brief, to ensure that Alex received any better treatment, or shifted up the ‘waiting line’ for a funding package or a place in a funded group home.

Wendy (pseudonym) is a 54 year old woman who has both an intellectual disability and a psychiatric illness. She lived with her parents until they died and she has since then lived in various Supported Residential Services (SRS) which are privately owned and operated facilities registered to operate in Victoria. Half of all SRS’s operate by charging a fee equal to the full disability pension. The remainder charge above the pension. 21% of the pension level facilities are employing a proportion of unqualified staff with 9% of all staff being unqualified across the sector. (Dept Health SRS census 2013)

Wendy has not been appropriately supported or housed since leaving the family home. Her extended family provides support weekly but cannot meet all her needs. Wendy has delusions that over time have become quite fixed and this can lead her to act in ways that risk her safety. She has absconded from SRSs and their low staff ratio and inability to safely support her has led to a number of long term hospital admissions to psychiatric units. Treatment there such as ECT and medication has not altered her fixed delusions and the primary reason she has stayed an inpatient is lack of alternate appropriate accommodation with supervision and support.

Wendy is on the waiting list for both funded supported accommodation (group home) regulated under The Disability Act and an individual support package and in the meantime has been discharged to another SRS. While the staff there does a mostly good job there is a low ratio of staff to residents and they are not properly qualified support Wendy.

During a family visit, Wendy told a family member she had been given two injections instead of one. The staff at the SRS said they knew the Community mental health service had visited twice and given two injections instead of the usual one injection but they didn’t know why and didn’t ask. When the family member checked with the community mental health service they acknowledged a staff member had not signed for the first injection and so a second was given by mistake. The health service had given the SRS medication for Wendy to counteract the side effects of the overdose but they hadn’t told staff at the SRS what this medication was for or written this medication on the drug chart. This was possibly because they were trying to cover up the initial mistake. The SRS staff believed this additional medication was for when Wendy was angry and had been dispensing it on this basis. In fact it was to stop side effects including shaking hands. The family met with the Community mental health service to discuss the failings and received an apology but they remain concerned that such a series of errors could have occurred and that the SRS staff is not equipped to pick up on and act on this neglect. The impact for Wendy was significant but could have been disastrous.

The majority of SRS residents, 88%, do not manage their own medication and in 68% of cases SRS staff manage resident medication. SRS staff routinely dispense medication to Wendy and family members have found it in the bin in Wendy’s room. SRS staff don’t check to see if Wendy is throwing out her medication or put in place strategies to keep encouraging her to take it. As a result medication is rarely stable for Wendy reducing its effectiveness which impacts on her wellness and behaviour. Her family continues to advocate for Wendy to be better supported but worry about what will happen when they aren’t able to do this.

George (pseudonym) is a 37 year old man with autism and intellectual disability who lives in a funded group home regulated under The Disability Act operated by a non-government disability service provider. George’s family sought and received advocacy support to attempt to get a response with regard to a letter of complaint they had sent to the disability service provider regarding incidents they become aware of. The family had lodged a Freedom Of Information (FOI) request for incident reports regarding their son as they had no explanation for deterioration in his mobility. The FOI revealed two incident reports where their son had been found on the roof of the building by staff and that in one incident while being coaxed down he fell and got his foot stuck in the gutter. The family had never been told about these incidents or whether medical attention was sought.

Because their son’s condition had deteriorated and he was having dangerous falls getting out of bed and the bus, the family had tried to communicate with the service provider about the possible reasons for their son’s condition and what support he needed. The service never offered any information about injuries George had received that could explain this. The family experienced resistance from the service provider to ideas for improvement such as underlay carpet which the Occupation Therapist recommended. This was refused due to cost so the family offered to purchase a foam mat to put on the floor by the bed as George had frequently fallen out of bed onto a hard floor. The service would not allow the mat to be used despite the risk to George until an additional Occupation Therapist report specifically recommended a mat. Getting this further appointment took more than a month but the mat was finally approved.

The family was frustrated and suspicious at this obstruction and thus applied for incident reports through FOI. They had not been told of the incidents they discovered including their son being on and falling from the roof. When the incident reports were pointed out to the service provider the initial response from the Program manager was that this happened before her time and she couldn’t therefore know what happened. After it was explained that a response was sought from the organization, not her personally, she agreed to look at and consider documentation that exists. Her written response was that the incident reports didn’t indicate if an injury had occurred although they mentioned a “red belly” and she was unable to verify that a medical review occurred after the incident. She did not respond as to why the family was not informed at the time although she did say she was confident all current concerns regarding their son have been communicated to the family and concerns discussed. The family was not happy with this response.

Not long after this the father observed staff contravening a management and Occupational Therapist approved two person support plan for assisting their son getting off a bus. George had had several serious falls getting off the service owned minibus. When George’s father raised this with the new house manager this person claimed not to know about the agreed procedure and that it was not on the clients file. After again complaining to the Program manager and providing copies of the minutes of our advocacy meeting where this was agreed to and recommended by an

Occupational Therapist, the Program manager acknowledged a staff members mistake and agreed to direct the house supervisor and workers involved to use a 2 person support method. The family remains completely unconvinced of the professionalism of the service provider and lacks confidence in the service's ability to appropriately investigate, respond to and follow up complaints of neglect let alone put in place every day supports recommended by medical professionals. They have no faith that they will be informed if incidents occur. They are questioning whether they should seek another service provider but against this are that their son has autism and doesn't cope with change and he likes and gets along with the people he shares his house with. Also there are no other funded group homes regulated under The Disability Act in the area or vacancies in other services further afield and families are well aware that any service is better than no service. The waiting list to get into funded group houses regulated under The Disability Act is in the thousands.

George's family continues to negotiate with the service provider to try to ensure he is safe from further injury. This process so far has taken nearly 2 years. Every suggestion they make must go through a slow bureaucratic process. Occupational Therapy can take 4 months to get an appointment. Even when plans are approved, staff are not fully informed or supervised to follow them. Some staff have spoken up and agreed with George's family that processes aren't safe and alternatives are needed. These staff, who have expressed their views as professionals with experience, have then been reprimanded by supervisors for saying something that was in support of change.

c) the incidence and prevalence of all forms of violence, abuse and neglect perpetrated against people with disability in institutional and residential settings;

Evidence of the marginalization of PWD can be found in research that suggests that PWD experience abuse at rates 4 to 10 times higher than the rate for people without disabilities. The rate of abuse directed at people with disabilities (PWD) is often hard to document for many reasons including the fact that historically data on disability status has not been collected in databases tracking crime and victimization. Furthermore, the media often fails to cover these situations, keeping the problem hidden from view. Another factor in the hidden nature of abuse is that research suggests PWD often cannot or chose not to report abuse and when they do report, their claims are often disregarded. (West B, Ghandi S, 2006)

People with disabilities who live in institutions and residential settings are particularly susceptible to violence from staff and other residents. This violence is very difficult to detect, investigate and prosecute. (French, P., Dardel, J., Price-Kelly, S. (2009*))*

Many disabled people can speak up for themselves to complain, report abuse and get access to an advocate but not everyone can and there are significant barriers such as cognitive ability and communication impairment. However the most disabling factor preventing the reporting of abuse is the control paid carers and disability services have over clients and their vulnerability given the likelihood that perpetrators of abuse are also the providers of needed daily support. There is legitimate fear of reprisals held by clients of disability services. The reprisals can include further abuse, restrictive practices, lack of choice in the house or lack of involvement in decision making over matters affecting the person. Other negative reprisals may be withdrawal of favoured activities, lack of support in a timely way, restriction of meals etc. Reprisals can also be quite subtle such as unpleasant mood or tone of voice of the carer or lack of attention in general given by the carer to the client (cold shoulder treatment).

People become institutionalised by this manipulative treatment and often try to predict what the carer wants them to say or choose, so as to avoid negative consequences. Even good workers and services find that clients are reluctant to complain and prefer to please. In disability services the power to decide often lays with the service provider because of duty of care. This power is understood by clients. A culture of control, dominance by single service providers, isolation, lack of frequent independent oversight, lack of access to advocates or other community members has been a feature of disability services. There cannot be too much independent oversight to counter this and while registration and quality standards checking will help it is only quite recent and practices are entrenched. Isolation of people with a disability in residential and day services compounds this culture and control.

The 'closed' nature of institutions and residential settings prevents public scrutiny, and creates greater risks – people with disability are unable to report violence to staff that may be the perpetrators of violence or where disclosure will lead to further violence. (Civil Society CRPD Parallel Report Group (2012))

d) the responses to violence, abuse and neglect against people with disability, as well as to whistleblowers, by every organisational level of institutions and residential settings, including governance, risk management and reporting practices;

AMIDA advocates for many clients in groups homes and SRSs and we often observe reluctance on the part of service providers to be open to discussion on issues of concern, let alone take action to change their procedures. We have seen with the Royal Commission into Institutional Child Sexual Abuse that organisations have defended themselves at the expense of victims of abuse. Our concern is the impact of a Disability Service culture which displays a defensive approach to any criticism and to downplay and smooth over what are valid concerns and complaints about neglect, poor reporting, poor communication and poor follow up. While disability services continue to operate in this way they risk neglect and abuse occurring and continuing, for which people with disability will pay the price. Dominant policy and practice approaches do not give adequate consideration to the prevention and protection of people from harm, focusing primarily on responding to individual instances of maltreatment. Managerial, compliance-based systems may be deflecting attention from recognizing and responding more effectively to abuse and neglect at individual, systemic and structural levels. The current dominant approach fails to develop a culture of prevention and protection for people with intellectual disability. Further, some systemic and structural preconditions are set which make abuse and neglect less likely to be prevented. (Robinson S, Chenowith L. 2011)

e) the different legal, regulatory, policy, governance and data collection frameworks and practices across the Commonwealth, states and territories to address and prevent violence, abuse and neglect against people with disability;

Much work is needed in this area and with the introduction of the NDIS there is scope for common safeguarding processes and structures. It is important that the highest standards become the national framework and not the lowest common denominator. A common policy goal to close and dismantle and cease to support institutional residential services is required and this should be incorporated into all national and state action strategies.

f) Australia's compliance with its international obligations as they apply to the rights of people with disability;

Institutions by their very nature perpetuate abuse (Sobsey, 1994).

Under the UN Convention on the Rights of Persons with a disability are the following articles

Article 16 - Freedom from exploitation, violence and abuse

Article 19 - Living independently and being included in the community

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

a. Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
b. Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
c. Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their need

Public and private institutions, which congregate and segregate people with disability for large periods of their lives, must be closed in order for Australia to comply with the UNCRPD. In addition smaller group homes need to allow people choice of who they live with, where they live and more control over decisions affecting them in the place they live.

g) role and challenges of formal and informal disability advocacy in preventing and responding to violence, abuse and neglect against people with disability;

AMIDA was funded a small amount by Victorian DHHS of $30,000 per year for two years to provide information peer to peer training to residents in shared supported accommodation about their rights in the service, including their right to be free of threats, harassment, bullying, violence and abuse. People with disability in residential services are isolated, vulnerable, uninformed about rights and advocacy and staff have power over them. In the course of going out to 86 different houses we provided accessible information that was relevant to their experiences in residential settings. In the discussion that took place we had numerous instances of abuse disclosed to us and were able to advocate for the individuals to remedy the situations.

The funding we received was used to provide accessible information and face to face training to residents which provided many with an opportunity to discuss abuse with advocates. This had never happened for any of them before. Most people with a disability in shared supported accommodation live lives closely controlled and influenced by services providers which have a vested interest in complaints not being made. AMIDA found it extremely difficult to access these properties because of service provider resistance and worked hard to be able to do so. These services were able to hide behind standards of privacy as the residents addresses could not be provided to AMIDA. When we did have our information delivered to houses via a middle manager, we had no confidence the residents actually received the information or were told of our wish to visit them.

Unfortunately the funding was of a one off nature and we have not been refunded despite requests to DHHS and the Office for Disability and support for the project from Victorian Office of the Public Advocate and reports from Office of Disability Services Commissioner that say this type of peer education program actually prevents as well as reveals abuse. There are 1000 shared supported accommodation homes in Victoria with around 5000 residents and we were only able to visit 86 houses. In so doing we were made aware of numerous cases of abuse that had not been reported to community visitors or anyone else.

This is because we had time without staff present where we provided information specific to rights, presented by people with a disability and in a very accessible way that people understood. We made repeat visits and people trusted us as advocates who were independent of the service provider and who were on the resident's side to help them resolve the issue. We support the Victorian Community Visitors program as another independent source of monitoring disability services. While Community Visitors can observe and report on practices in residential services they are not able to be partisan. Advocacy is partisan and we state we are clearly on the side of people with a disability. Our, 'Know Your Rights' education program provided a context for explaining what rights and abuse are, followed by discussion of residents experience of rights and abuse. Residents told us about abuse because no-one had ever come to them and explained what abuse was and talked to them about rights and abuse before. We provided a safe opportunity to talk about rights and abuse with peers which is unlike any they had previously had. **Our concern is, if this type of peer rights training and discussion is not provided, many people with a disability who are will never have the opportunity to safely report abuse and so abuse will go unreported.**

h) what should be done to eliminate barriers for responding to violence, abuse and neglect perpetrated against people with disability in institutional and residential settings, including addressing failures in, and barriers to, reporting, investigating and responding to allegations and incidents of violence and abuse about their rights;

One barrier is access to advocacy by people with a disability. We must also ask why service providers don't invite advocacy. AMIDA's experience is that it is difficult to gain entry to group homes, work places or day services to deliver information about their rights that people with disability won't otherwise have. Approaches are made to all these services, and instead of welcoming the opportunity for information to be made available for the people they work with, services are often obstructive. They are defensive of any criticism of their service and dismissive of proposals for improvements that will benefit people with disabilities. We have seen with the Royal Commission into Institutional Abuse that organisations have a tendency to defend the organisations interests at the expense of the victim of abuse. As a community we must acknowledge this tendency and introduce additional safeguards around access of advocacy to all services. Independent advocacy should have a right of entry to all disability services in order to offer our advocacy support directly to service users rather than have to go through service providers with a vested interest in excluding us.

Legislative right to enter services should be created to allow advocacy services to come in and offer to provide people with information about their rights. Services cite privacy concerns when they refuse to give addresses of residential services. Services must give right of entry to advocacy services who can directly ask clients if they want information, and they must allow a mailing house intermediary to have the addresses in order to supply people with disability with independent rights information and information about advocacy services, self-advocacy and self-advocacy groups.

i) what needs to be done to protect people with disability from violence, abuse and neglect in institutional and residential settings in the future, including best practice in regards to prevention, effective reporting and responses;

Incident Reporting.

DHHS has a thorough process of incident reporting and handling. Improvement can and should be made and the Victorian Ombudsman is currently reviewing this system. It is different from complaints handling but equally as vital and has been neglected in the consultation paper on a Quality Safeguards System under the NDIS by DSS. The Victorian approach to incident reporting is worth highlighting and should be emphasized in any negotiations around the NDIS.

AMIDA believes the Victorian system of incident reporting could be adopted nationally if improved in a couple of key ways. Sequential numbering of incident reports does not currently happen at the service level only once reports have been forwarded to DHHS. So, for example, if a report is missing from the sequenced pages in a residential service this absence cannot currently be detected. Presently Community Visitors who have access to house records cannot see if initial incident reports have been destroyed. Also incidents are categorized according to seriousness but only the highest categories have to be reported to the funding body. All incidents of harm need to be acknowledged and acted on so all incidents should be reportable to either the funding body or an Independent Complaints Body. Incident Reporting is vital because people with a disability usually don’t or can’t complain.

Provider registration requirements;

AMIDA supports mandated participation in an external quality assurance system for providers of supports. Presently, the Quality Audits against the National Standards for Disability Services are a thorough, independent way to assess services. Within the audit there are reportable actions. AMIDA has grave concern that if thorough, independent audit is not carried out and continued, then poor/bad practices will not be discovered and corrected. Systematic audits including reportable actions must be incorporated into the NDIS to ensure regular checks of service provision to people with disability. The present audits have ensured our service has improved its practices, and continues to do so.

Current practice is that Auditors refer instances of non-compliance or reportable incidents to DHHS in Victoria and the funding body works with services to bring them up to acceptable levels. The Auditor is somewhat limited in this their ability to continue working with services to get improvement. NDIS should take on this role under the national roll out so people with disability have consistent services and non-compliance is addressed.

More access to advocacy and self-advocacy and information for people with disability and opportunities to learn about and discuss rights assists people to confidently raise issues of concern. Prevention and reporting of neglect and abuse can be improved with the support of independent advocacy services which can provide information and support to people with disabilities wanting to complain and participate in audits.

Nevertheless just having a place to complain is not enough. People with disability must be continually encouraged to complain where necessary and be supported to do so. Advocacy organisations can support people with disabilities to make complaints and follow them up.
Advocacy can provide education and also follow up complaints directly with service providers and/or formally to an independent body like the Office for the Disability Services Commissioner or the Ombudsman. An additional obstacle to people with disability making complaints is that people are often

reluctant to complain for fear there will be repercussions, or they have been unsuccessful in previous complaints and are worn down by previous endeavours. A major component of a complaints handling system must be the availability of disability advocacy.

Systemic and structural changes are also necessary to prevent abuse. Research into cluster housing and resident group size is now showing that, on a whole range of measures, people with a disability do better in dispersed housing with small resident group sizes. This research also does not support the development of cluster housing. We direct you particularly to the report “Presenting the Evidence: Accommodation and Support for People with Disability” by The Institute for Family Advocacy and Support. This research was undertaken by Family Advocacy NSW in collaboration with Lesley Chenowith from the University of Queensland and Trudy Van Dam from the Australian Catholic University. They reviewed academic and research literature on this topic and looked at cost effectiveness, staffing, supporting challenging behaviour, supporting people with complex health needs and self-management of funds. The overwhelming conclusion from the research is that larger forms of accommodation offer significantly poorer quality of life for people with disability than smaller forms of accommodation. In fact a number of housing models such as cluster options or villages, inner city town houses, complex behaviour units and 8-10 bed units are not supported by the literature examined in this review. Research has in fact shown that the larger the staff: resident group, the lower the level of resident activity and resident gains were found when the resident group size was reduced (Felce: 1998:110). Evidence leads to a number of policy directions for Government in the area of accommodation and support including;

- the need for small dispersed housing and supported living schemes
- more focus on the way staff provide support
- more evidence based ways to support those with challenging behaviour including a move to smaller groupings that don’t congregate people with challenging behaviour
- develop services and supports to enable people with complex health needs to live in the community
- greater opportunities for people with disability and their families to have control of the funding allocated (Institute for Family Advocacy and Leadership Development, 2006:7)

j) identifying the systemic workforce issues contributing to the violence, abuse and neglect of people with disability and how these can be addressed;

AMIDA supports the current Victorian DHHS worker safety screening requirements. The NDIS must incorporate Police check, Working with Children Check (if relevant to the role), a check against the Disability Worker Exclusion List, a Disqualified Carer Check, Employment History Check (including disciplinary action disclosure and checks of qualification and training). This is vital to ensure the safety of people with disability.

Much needs to be done to train workforces in disability services about appropriate support that is person centred and fosters independent decision making and choice. Understanding the way power affects the client/worker interaction is vital. Understanding respectful ways of working and rights to be safe and feel safe are fundamental.

Training, induction and supervision are vital and yet the standards expected are not high enough in AMIDA’s view. In our experience it is difficult to substantiate claims of abuse when workers are on shifts alone. As much as possible sole workers should be discouraged. This will act to prevent abuse as well as it removes the opportunity to abuse.

While it is good that in some cases the workers complained about are moved away from direct contact with our clients, it is concerning that often they are still working with other vulnerable people while these matters were being investigated. Internal service investigations differ and there is not always suspension of the alleged perpetrator, nor is there guaranteed shadowing of this worker while they continued to work with other vulnerable clients.

Even though the complaints of abuse are often found to be unsubstantiated because no one else witnessed the alleged abuse, the complaints were not disproved and it is possible that the alleged abuse did in fact take place and the perpetrators are still working with vulnerable people. This is extremely concerning. Many encounters between staff and people with a disability happen without other witnesses. This is sometimes to maintain client privacy but is also due to lack of adequate resources to employ more staffing who could monitor each other. Even in shared spaces in residential services there may only be one staff member working with a number of clients and no other monitoring by staff of what is taking place.

There is also pressure put by staff on each other and residents to not write up or talk about incidents that occur. Bullying and a culture of “don’t dob in your mates”, is a problem for monitoring and reporting abuse and neglect. There is a need for more training of new and existing staff to counter attitudes that allow unnecessary restrictions and abuse to go unreported.

k) the role of the Commonwealth, states and territories in preventing violence and abuse against people with disability;

This responsibility is a shared one with all governments having to act to close institutions and take other positive actions. Cooperation across state boarders is necessary to have common regulation, registration, complaints bodies and enforcement of these. Reports on the issue of abuse in residential services are not new. In September 1996 the Commonwealth of Australia commissioned a report on this issue, “Abuse and Adults with intellectual disability living in Residential Services” by the National Council on Intellectual Disability and Australian Society for the Study of intellectual Disability. The report by Conway, Bergin and Thornton from the University of Newcastle looked at much the same terms of reference as this current Senate Inquiry. They made findings that “abuse is inextricably linked to the operational practises within services and is systemic”. They made recommendations on policy, training, employment and the need for unimpeded, independent advocacy. It is 20 years later now and we are still asking the same questions when the answers have been raised and reported on again and again. Urgent action is required now by all levels of government.

l) the challenges that arise from moving towards an individualised funding arrangement, like the National Disability Insurance Scheme, including the capacity of service providers to identify, respond to and prevent instances of violence, abuse and neglect against people with disability;

Incident Reporting as previously discussed is also vital because people with a disability usually don’t or can’t complain but observed incidents can be recorded and investigated.

Internal responses by service providers to complaints of abuse and neglect often are defensive and seek to protect the organization. Information isn’t always provided to families about incidents and they don’t know these reports exist. Much documentation can be missing as there is no numbering of incidents at the house level and they can quite easily be destroyed without trace. They are only numbered when they reach the level of being reported to DHHS.

Services know that users of shared supported accommodation have no meaningful choice of service to shop around for as they are in great demand and vacancies are managed by DHHS on a crisis driven system. Thousands of people are waiting for this accommodation option. Because service users do not have the option of simply leaving and easily acquiring another service, providers have no motivation to keep service users choosing their service. Increased funding to expand the range of housing and residential services available to people with a disability is desperately needed. This was one of the findings of the Victorian parliamentary Inquiry into Supported Accommodation for Victorians with a disability and/or mental illness in 2009. The increase has been minimal however and solely the result of replacement of closed institutional beds. While further closure of institutions was welcome this did not increase the availability of accommodation and support.

Clickability is an Australian disability service directory that features ratings and reviews from the people who actually use the services. The capacity to share reviews of services could be the beginning of another factor that encourages service improvement but only if there are more services to choose from. Potentially a service review will pick up instances of abuse and could be a useful safeguard in the individualised funding framework of the NDIS.

In our experience, services and their workers don’t always ask themselves first whether actions they take are respecting people’s human rights, are least restrictive and are best practice. Many do what is convenient given the demands placed on them and operate from a position of power over clients. They operate free from scrutiny most of the time and collude with each other to reduce threats to them. It is extremely rare that any service provider has ceased or lost funding because of abuse or even poor management of its aftermath. In an environment of increased housing and support availability governments will be less reluctant to sanction service providers or even deregister or defund them.

Independent oversight is vital. Some large service providers are now contracting out investigations of abuse. We have no guarantee that the investigations carried out internally by services or by independent investigators they contracted were broad enough. Other staff or clients may not have been asked about their experience of the alleged perpetrator but may have had vital information they had not shared because of their vulnerable situation and or difficulty communicating. Given the vulnerability of people with a disability the investigations should be broad to “door knock” other potential witnesses or similar experiences including from other clients and staff. While confidentiality of the complainant must be maintained if they wish it, this should not be used as an obstruction to a though investigation. A properly empowered Complaint handling and investigation service would be preferable to privately contracted agencies currently doing this work.

Independent investigation and freedom from conflict of interest is vital. However the independent investigators from a private company do their investigation for the service provider and reported findings to the service provider. The private investigators client is the service provider.

The Victorian Disability Services Commissioner has the power to investigate allegations and reports of abuse but has not conducted any investigations. They operate primarily as a mediator and educator and while this has value there is a desperate need for independent investigation of reports of abuse and they are empowered to do so yet choose not to. Under a national system, an office capable and willing to investigate, with powers to demand documents and interview potential witnesses is needed.

Funded disability service providers in Victoria are required to carry out extensive safety screening. Those funded services that use agency staff are now required to obtain written confirmation from the agency that they have carried out a similar level of safety screening of their staff. This requirement could become part of the national quality framework. For individuals managing their own funding package and using agencies not registered with NDIS, they could be given a tool kit which includes suggested procedures for selecting agencies. One point of this checklist could be that agencies provided written confirmation that staff they employ have been safety screened at the same level as required by NDIS registered services.

and

m) what elements are required in a national quality framework that can safeguard people with disability from violence, abuse and neglect in institutional and residential settings.

As said above, safety screening of all registered service staff is needed such as Safety screening incorporating referee checks and the police record check. It may also include a Working with Children Check (if relevant to the role), a check against the Disability Worker Exclusion List, a Disqualified Carer Check, Employment History Check (including disciplinary action disclosure and checks of qualification and training).

In terms of Independent Disability Complaints office is the best option that would provide the safeguards that people with disability require in the transition to NDIS. An independent body to oversee complaints is vital. It must also have investigatory powers and be willing to use them. If the Independent Disability Complaints office is established it should have at least all the current roles of the Disability Services Commissioner such as compiling of complaints made directly to service providers.
The complaints body must have the power to not only investigate complaints, but to require changes and adjustments to disability services which are found to be in contravention of human rights, legislation and regulation.

As the NDIS rolls out around Australia it must be acknowledged that Victoria has traditionally had strong safeguards, with accompanying opportunities for complaint, ie, the creation of the Office of the Disability Services Commissioner, Office of the Public Advocate, Senior Practitioners Office and the Ombudsman. These offices presently accept complaints about disability services, and investigate, and recommend liaison with service providers by users. They also provide advice and suggestions for improving relations between users of services and service providers. If this is not the case in other states, then it must be ensured that other states are required to set up similar bodies. Standards must not be lowered to bring them into line with systems with lesser safeguards in place.

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