



3 July 2015

Dear Sir/Madam

RE: VIOLENCE, ABUSE AND NEGLECT AGAINST PEOPLE WITH DISABILITY IN INSTITUTIONAL AND RESIDENTIAL SETTINGS, INCLUDING THE GENDER AND AGE RELATED DIMENSIONS, AND THE PARTICULAR SITUATION OF ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE WITH DISABILITY, AND CULTURALLY AND LINGUISTICALLY DIVERSE PEOPLE WITH DISABILITY

The ACT Disability Aged Carer and Advocacy Service (ADACAS) provides advocacy to people with disability, older people, people with mental health issues and their carers. ADACAS welcomes the inquiry by the Committee into violence, abuse and neglect against people with disability in institutional and residential settings. This is a concerning issue, which calls for immediate attention and redress, and we hope that the inquiry can contribute in some positive way towards achieving this objective.

Institutional living is characterised by a number of features, including imbalance of power between care recipient and carer, lack of choice, regimented routines, congregate living, and separation from community life. It can occur in a traditional institutional setting or continue to exist as institutional features despite a seemingly domestic residential setting. Any place where a person's life is largely controlled by service providers can be an institution and therefore be a setting where abuse and neglect becomes more likely.

ADACAS advocates have represented clients who have suffered from institutional abuse and we believe that it is imperative that such an issue be brought to light and addressed in the public domain. Cases like the one of systemic institutional abuse of people with disability by Yooralla, one of the largest non-profit disability service organisations in Australia, highlight that the need for protection and support of people with a disability in institutions is ongoing. ADACAS has provided advocacy support to many clients with a disability to deal with abuse that they have suffered.

Case Study: Jill

Jill suffers from a disability, which means she spends each day either in bed or in her wheelchair. Although she is only in her forties she is forced to live in a residential aged care facility as she requires 24-hour support from a carer.

The staff members at the nursing home where she lives treat Jill poorly. In moving Jill from her bed to her wheelchair one of them handles her roughly, causing an injury to her foot. When she needs help to change her soiled clothing her calls on the buzzer for a carer to come to assist, are frequently ignored. One carer swears at her when she asks for particular assistance and another blasphemes in front of her, causing great offence to Jill, who is a religious woman. She often misses scheduled showers and is dressed late when she needs to attend appointments or go out. Jill is too afraid to complain as she fears retribution from both the management and staff of the aged care facility.

An ADACAS advocate works to support Jill so that her concerns are properly addressed. The advocate brings the issues to the attention of management and ensures a system is in place whereby Jill can complain about her treatment and have it acted upon. Recognising that Jill is a younger person in an aged care facility the advocate applies to the local government housing agency to organise a shared house for Jill so that she can leave the nursing home. After a considerable amount of time on the waiting list Jill is offered a place in supported accommodation with other residents who also have a disability and who are closer to her in age. Jill is finally able to leave the nursing home and live in the community.

a. Human Rights Framework

The Convention on the Rights of Persons with Disabilities, 2006, was ratified by Australia on 17 July 2008. It contains a number of important provisions relating to the protection of people with disabilities from violence, abuse and neglect. Of particular relevance is Article 16(1), which states that State Parties shall take all measures to protect people with disabilities, both within and outside their homes, from all forms of exploitation, violence and abuse, including gender-based aspects. It is important to bear in mind the protection afforded by the Convention when considering the cases of people with disabilities who have suffered institutional abuse. In addition, there have been a number of rulings from different United Nations Committees that have highlighted the need for more action from the Australian government to support people with disabilities and prevent and protect them from institutional abuse¹. The current situation in Australia clearly highlights that the relevant provisions of the Convention are not being complied with and that urgent action needs to be taken to address this problem.

b. Institutional Abuse

ADACAS receives calls for advocacy support from people with disability and their families, who have suffered from institutional abuse. Below are two cases of clients we have assisted with advocacy in the past. They highlight how advocacy can go some way to having the person's voice heard in relation to the abuse they have suffered and also attempt to find a solution to stopping the abuse:

Case Study: Nicole

Nicole is a thirteen year old girl with an intellectual disability. Nicole is cared for by her mother, who regularly puts her in respite.

One day Nicole returns home from respite, traumatised and distressed. Nicole begins to talk to her mother about someone at respite having hurt her. She begins to express discomfort about being touched anywhere near the groin area. She says that she does not want to return to the respite centre and shows signs of bleeding from the vaginal area, even though she has not commenced menstruating. It is evident from the evidence that Nicole has suffered some form of sexual abuse while attending respite.

¹ See for example Committee of the Rights of Persons with Disabilities, *Concluding observations on the initial report of Australia*, UN Doc. CRPD/C/AUS/CO/1. (4 October 2013); Committee on the Elimination of Discrimination against Women, *Concluding Observations Australia*, UN Doc. CEDAW/C/AUS/CO/7. (30 July 2010);

An ADACAS advocate helped Nicole's mother by providing advocacy support for her and Nicole while the organisation investigated the allegation. Despite their best efforts the perpetrator of the abuse was never identified nor brought to justice.

The following case highlights that having the support of an advocate can help the person who has suffered abuse to articulate this abuse and have their fundamental human rights respected and recognised.

Case Study: Jacqueline

Jacqueline is a young woman with a disability, who uses a wheelchair. She lives in supported accommodation with other residents who also have a disability. The support workers who work at the house where Jacqueline lives do not take into consideration requests that she makes of them. She has a plan relating to her care and support, which the workers ignore and do not follow. She enjoys accessing hydrotherapy but her access is stopped. Sometimes Jacqueline's legs kick involuntarily at night and cause her pain, as her bed is located next to a wall. She fears that she might hurt herself and needs someone to move her legs or give her pain relief medication but her requests in this regard are repeatedly ignored. She is fearful that one night she might accidentally fall out of bed and no one will come to her assistance. The lack of reliable support and consistent ignoring of her requests causes great concern to Jacqueline. She feels neglected and accesses support from an advocate with a view to communicating her concerns to the organisation and improving the quality of care that she is receiving. They work together until Jacqueline's standard of care improves and her rights are respected by her new carers.

c. Fear of Retribution

One of the greatest fears that a person with a disability who has suffered abuse in institutional or residential facilities frequently may have is of lodging a complaint against the very person who is entrusted to care for that person. If a complaint is lodged but the person against whom the complaint is made continues to provide care for the person who has been abused this can create a situation of great trauma and fear in the complainant. For this reason, when a complaint of abuse is made it is imperative that the carer who is accused of having committed an abusive act is immediately suspended from their duties, pending a full and thorough investigation of the allegation made against them. While such a practice may appear to be common sense, the Yooralla case highlighted that this does not always happen, i.e. that investigations of complaints are frequently not conducted and that people who are accused of engaging in abusive acts are not always automatically suspended pending further investigation.

Case Study: Abuse by a Nursing Home

ADACAS had a number of clients seeking advocacy support from a particular residential aged care facility in Canberra. As the clients shared a number of similar issues and complaints regarding their treatment by the staff at the nursing home ADACAS decided to lodge a group complaint against the nursing home to the Aged Care Complaints Scheme. The complaint included staff not providing residents with adequate pain management and leaving them to suffer in pain without treatment; staff speaking in an abusive manner

with residents; providing residents with food of a substandard quality and insufficient amounts; not respecting the privacy of clients by leaving them undressed and exposed to other residents and staff; failing to respect the privacy of residents; and not properly managing residents' incontinence so as to leave them for hours sitting in soiled garments. As the people who had instigated the abuse were the carers of the complainants, the residents were fearful of retribution for complaining about how they were being treated. As a result, ADACAS was compelled to lodge the complaint to the Scheme without naming who the complainants were.

After investigation by the Scheme the nursing home were compelled to take steps to educate and better train their staff so that the standard of care ultimately improved.

d. Avoiding Prosecution

It is a common scenario that perpetrators of violence and abuse against people with disabilities in institution will change employers as a means of avoiding being caught and also as an opportunistic means to continue abusing against even more vulnerable people. Katrina's case highlights the lack of prosecution of perpetrators of abuse:

Case Study: Katrina

Katrina is a frail older woman, who is in her nineties. She has some issues with mobility and lives in a residential aged care facility. One day, Katrina goes to the kitchen area of the facility to make herself a cup of coffee. While she is there a carer approaches her and forcibly shoves her in a corner, and touches her in the genital region. He mocks her and says that if she dares to complain no one will believe her and says that he will be back to give her more. Katrina is shocked by how the carer treated her. She feels afraid to go anywhere in the facility and becomes depressed. She tells a friend and a family member about the incident. The family do not want her to take the matter further but the friend supports her to contact ADACAS.

An advocate is assigned to represent her. A complaint is made to the management as well as the Aged Care Complaints Scheme about the incident. While the process is taking place the carer resigns from working at the facility. Katrina is told that they have heard that he now works in another aged care facility as a carer. There is no further action that is taken against the carer. Katrina informs the police about the incident but she is frail and elderly and suffers from some cognitive impairment and can provide no other witnesses to the incident. They decline to take the matter further and do not seek prosecution of the perpetrator of the abuse.

Processes must be put in place in institutions, whereby an investigation does not stop merely because an alleged perpetrator has changed employment. Victims of abuse must be supported to overcome the abuse they have suffered and lodge a complaint, if that is the course of action that they wish to pursue.

e. Lack of a Comprehensive Definition

The difficulty with people with disabilities living in institutions is that any violence or abuse that they may suffer does not fall within the traditional and legal definition of 'domestic violence'. Without recognition that this falls within the definition of domestic violence, people with disability who suffer such abuse are at increased risk as the legal support they may access to combat the violence is effectively denied to them². While domestic violence is often in the media spotlight recently, violence in the homes of people with disability is still not understood or recognised as domestic violence. ADACAS is aware of cases of adults with disability who are physically and psychologically abusing their older parents; and of cases where residents of supported accommodation or other institutions experience abuse perpetrated by other residents. In both cases there are significant barriers to reporting and addressing these incidences of domestic violence. In addition, domestic violence support services may not be available to the victims because the abuse does not fall within the common definitions of domestic violence.

Case Study: Mark

Mark is a young man who has a profound disability, autism, a learning disability, is mute and uses a wheelchair. He lives in supported accommodation with two other men and Sue, who also have disabilities. Sue is violent and has frequent outbursts whereby she physically assaults the other men, destroys the private property of the other residents in the house and punches holes in the walls. Mark's family would often find bruising on Mark's body, when they came to visit him. They reported this to the organisation that managed the home but nothing was done to rectify the situation. In desperation Mark's family reported the abuse to the police. The police came, took photographs and interviewed staff. The matter was eventually taken to court and an ADACAS advocate supported Mark through this process. Eventually the court decided that Sue was to be evicted from the house.

f. The Situation of People from Culturally and Linguistically Diverse (CALD) Backgrounds

People from CALD backgrounds with a disability may experience even greater difficulties in reporting abuse. Language challenges including an inability to express oneself in English may make it problematic for a person from a CALD background to report abuse they may have suffered. Cultural traditions may render the person with a disability to be regarded as someone with lesser value than a person without a disability and thus make it difficult to rely on family members or people from the same community to act upon any reports of abuse. For this reason it is important to ensure that workers are provided with cross-cultural training, so that they are better able to respond to the needs of the person and possibly be alert for potential complaints of abuse. The use of independent interpreters is also important, to ensure that the person is able to accurately relay his/her account of abuse in their own language.

² Senate Standing Committee on Finance and Public Administration 'Inquiry into Domestic Violence in Australia', Joint Submission from National Cross-Disability Disabled People's Organisations (DPO's), September 2014, p.16.

Case Study: Tania

Tania is an elderly woman from a European country who lives at home. She suffers from a number of physical ailments, which make it difficult for her to move around. She is able to continue living at home because she receives carer support from a community organisation. Without the support she would not be able to live at home and would be forced to move to a residential aged care facility, an option she does not wish to pursue.

Tania would like some more support. She approaches her case manager to negotiate a way forward so that she can receive more support on her limited pension income. The manager is rude and abrupt and refuses to work with Tania to find a more affordable way forward so that Tania can continue living at home. She starts to pressure Tania to move to a nursing home, goading her by saying that Tania cannot cope living by herself at home. Tania becomes increasingly afraid and concerned that she is being forced out of the community support program and will be forced to live in a nursing home because the case manager is unwilling to explore options with her. She begins to feel fearful of the case manager and somewhat bullied by her approach.

Tania seeks advocacy support from an ADACAS advocate who is able to speak her native language. Together they explore the problems that Tania is facing. They attend meetings with the staff of the organisation and manage to negotiate a way forward so that Tania can continue to receive the support that she needs.

g. The Situation of Persons from Aboriginal and Torres Strait Islander People

Once again it is important for people from an aboriginal or Torres Strait Islander background to be able to feel comfortable to relay accounts of abuse in a context of cultural understanding and support. Thus workers should be provided with cross-cultural training specifically targeting the support of clients from aboriginal and Torres Strait islander people. As some indigenous people may have suffered in the past from adverse interactions with institutions e.g. the Stolen Generation, the prison system etcetera it may be challenging for many indigenous people to feel safe in recounting abusive experiences. Thus, trained and culturally aware staff as well as a supportive environment that does not tolerate abuse, are initiatives that should be pursued in this regard.

Case Study: Colleen and Sue

Colleen and Sue are elderly indigenous women. They live at home and require support to enable them to continue living at home. They receive support from an indigenous organisation that provides carers' support for elderly indigenous people.

Colleen and Sue both are unhappy with the quality of services that they receive from this organisation. They make a complaint about their concerns regarding particular carers with whom they are dissatisfied. The service provider abruptly, and without notice, withdraws the service support that they receive. This leaves Colleen and Sue in a vulnerable position, as it is difficult for them to continue to live at home without receiving the support that they require. The organisation is uncooperative and refuses to take any steps to resolve the issue.

Colleen and Sue seek advocacy support from an ADACAS advocate. The advocate works with both clients in an attempt to improve communication between them and the service provider. However, despite their collaboration and best efforts as of this date the service provider continues to refuse to provide the women with the support that they need.

h. Difficulties with Communication

Older people living in residential aged care facilities may find it difficult to recount experiences of abuse due to the presence of cognitive impairment as well as fear of retribution. People with disabilities may, by the very nature of their disability and their fear of retribution, find it hard to articulate issues that may concern them.

Case Study – George

George is a 32-year-old man with multiple sclerosis. As he is unable to care for himself and has no one to care or support him in the community he lives in an aged care facility. George has no one to talk to of his own age. The staff, when providing care support for him, would completely ignore him, and talk to each other as if he didn't exist. One of George's few pleasures in life consists of smoking but the staff would not permit George to smoke anywhere. The carers would frequently talk abusively to George. George suffered numerous falls. He was afraid to have a shower as on one occasion a carer had not supported him properly and he had fallen in the shower. The government eventually built specially modified houses for younger people with a disability living in nursing homes and George, with the help of advocacy support, eventually moved out of the nursing home into the government house.

i. Training

Training of staff in communicating effectively with people who suffer from some form of cognitive impairment as well as ensuring that residents live in a safe and supportive environment are key elements in being able to ensure that older people are able to confide in a worker about any negative experiences that they may have suffered. It cannot be assumed that all carers have the ability to effectively communicate with people who have disabilities and who may struggle to communicate and express their wishes. Older people with cognitive impairment may likewise find it difficult to express their wants and needs. Training courses in communicating with people suffering from cognitive impairment should be made obligatory for all staff members working in residential aged care facilities. By being able to communicate more effectively with workers people who suffer from abuse in institutions are more able to seek help in addressing the problem.

Case Study: Ivan

Ivan was a refugee from a country where he had suffered great persecution. He had been detained and tortured by the authorities before he managed to escape and seek asylum in Australia. In Australia he was in a car accident and consequently suffered from quadriplegia. Initially Ivan lived in a residential aged care facility where he was brutally raped by a male carer. Eventually Ivan moved out of the nursing home and lived in supported accommodation where he became fully dependent on his carers.

The quadriplegia made it difficult for Ivan to control the movement of his hands. Because he had been assaulted by a male Ivan requested that only female carers shower him. The carers, not understanding Ivan's special circumstances or the reasons behind his request, began to accuse Ivan of sexual harassment, which Ivan completely denied. The carers began speaking amongst themselves maliciously about Ivan until he was completely maligned and spoken to in a negative and derogatory way. The standard of care received by Ivan would often be poor. Carers would frequently arrive late for their shifts; they would not feed Ivan regularly. When Ivan would experience positive working relationships with carers who would communicate his issues to management those carers would be transferred to another job and replaced with new carers.

Eventually, with the support of an ADACAS advocate, Ivan complained about his treatment to the Human Rights Commission. He eventually received an apology from the care provider for how he had been treated.

j. Minimising Social Isolation and Inclusion

Social isolation is one of the main enablers of abuse and neglect. People with disability commonly experience social isolation. They may know and be known by very few people outside of family (if family are present) and paid workers. Connection to community, being known by others, is a significant safeguard against abuse and neglect. The more visible a person is in their community, the lower the likelihood that abuse can be hidden and ongoing. The NDIS presents opportunities to ensure that people have greater connection and visibility in their local communities and this may act as a safeguard against abuse. On its own however, it will not be sufficient. Social isolation of people with disability also has a cultural dimension and requires a cultural change approach. While ordinary Australians have little experience of people with disability, while they continue to view them as separate to and different from themselves, while our education, employment, justice, transport and health sectors continue to respond inappropriately to the needs of people with disabilities, social isolation will be perpetuated and abuse may not be abated.

k. Conclusion

It is evident from the evidence we have before us that the situation with regards to the abuse of people with disabilities from institutions continues and is not being adequately addressed. There is much that needs to be done. With major reform in the disability sector via the introduction of the National Disability Insurance Scheme, there are means whereby people with disability should be able to access greater supports to live a higher standard of living, which includes minimising the potential for abuse to arise in their lives. With a view to action and change with regards to this issue, we propose the following recommendations:

Recommendation 1:

Process for responding to allegations of abuse are improved, including:

- That people who are accused of abuse or neglect are immediately suspended and prevented from working in other organisations with vulnerable people, pending a finalisation of an independent investigation into the allegation
- that mechanisms are immediately put into place to ensure that the person who has made the complaint is protected from retribution and from having to interact with the alleged perpetrator of the abuse.
- Service providers must follow through to completion any investigations relating to abuse by a worker irrespective of whether or not the worker resigns subsequent to a complaint being made

Recommendation 2:

Reform of the criminal justice system so that it better accommodates and supports people with disabilities to be able to participate as complainants and witnesses. Government leadership and resources need to be focused on this area in order to affect urgent reform

Recommendation 3:

Improvement in the collection of data and research regarding prevalence, incidence and nature of abuse in terms of both monitoring and conducting research. Agencies need to resource this data collection and to this end engage in staff training;

Recommendation 4:

Agencies should be encouraged, funded and supported to create environments that prevent all forms of violence and neglect and enable disclosure, including improved access to sexuality education for people with disabilities.

Recommendation 5:

Greater resourcing of agencies supporting people with disabilities who have experienced abuse should be made available. This includes greater funding for advocacy organisations, so that people with disabilities can have a voice to articulate the abuse they have suffered and to access appropriate redress;

Recommendation 6:

The definition of domestic violence should be changed to include supported accommodation and institutional settings where people with disabilities live.

If we can be of further assistance to the Inquiry please contact Sonia DiMezza

Yours sincerely

Fiona May
CEO