



JFA Purple Orange

JFA Purple Orange Submission

To the Senate Standing Committee on Community Affairs' Inquiry on 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.

Submitter details

JFA Purple Orange

104 Greenhill Road

Unley SA 5061 AUSTRALIA

Telephone: + 61 (8) 8373 8333

Fax: + 61 (8) 8373 8373

Email: admin@purpleorange.org.au

Website: www.purpleorange.org.au

Facebook: www.facebook.com/jfapurpleorange

Contributors

Robbi Williams, CEO

Ann-Marie Loebel, Policy Officer

Jackie Hayes, Leader Social Policy and Initiatives

Kerry Telford, Research Officer

Glenda Lee, Project Officer

Margie Charlesworth, Convenor, Women with Disabilities South Australia

About the Submitter

JFA Purple Orange is the social policy arm of the Julia Farr Association Inc. We are a non-government, social profit organisation that conducts research and engages in dialogue with people with lived experience of disability to develop policy and practice. Our work is anchored on the principles of Personhood and Citizenship.

© April 2015 Julia Farr Association Inc.

Contents

1. Summary	5
2. Introduction	8
2.1. JFA Purple Orange	8
2.2. International and National Contexts.....	9
2.2.1. The United Nations Convention on the Rights of Persons with Disabilities	9
2.2.2. The National Disability Strategy	11
2.3. Key Principles	13
3. Our Approach to this Submission	15
3.1. Definitions	16
3.2. Terms of Reference (a) the experiences of people directly or indirectly affected by violence, abuse and neglect perpetrated against people with disability in institutional and residential contexts.....	17
3.3. TOR (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	19
3.3.1. Impact of gender	20
3.3.2. Abuse outside institutional settings.....	22
3.4. TOR (g) role and challenges of formal and informal disability advocacy in preventing and responding to violence, abuse and neglect against people with disability	23
3.5. TOR (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	25
3.5.1. Criminal justice system	29
3.6. TOR (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	31
3.6.1. Prevention.....	31
3.6.2. Reporting.....	35
3.7. TOR (j) identifying the systemic workforce issues contributing to the violence, abuse and neglect of people with disability and how these can be addressed	36
3.8. TOR (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.....	39

3.9. TOR (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 ..40

4. Conclusion..... 45

5. Recommendations..... 47

1. Summary

JFA Purple Orange is an independent, non-government organisation based in South Australia that fosters innovation, shares useful information and promotes policy and practice that support and improve the life chances of people living with disability.

JFA Purple Orange's submission to the Senate Standing Committee on Community Affairs endorses the United Nations Convention on the Rights of Persons with Disabilities and National Disability Strategy 2010-2020. We provide evidence to support the human rights imperative of preventing violence, neglect, and all forms of abuse inflicted upon people living with disability, regardless of their place of residence. We highlight that each individual must have power, choice and control over their own lives, within an inclusive society to effect any real and sustainable change, and that any systemic response must include measures that positively build a person's capacity and maximise the good in a person's life rather than focussing on avoiding bad things happening.

There are many short and long term actions that can be implemented to protect intrinsic human rights and reduce the risk of violent, abusive and neglectful situations for individuals living with disability. Safeguards may include a range of informal and formal supports and mechanisms operating at the level of the individual, the community, disability services and overarching government systems and legislation.

However, we must not lose sight of the causes of increased vulnerability to abuse and neglect. Prevention of abuse must occur in the context of person-centred support which increases inclusion, control and choice and supports an individual to manage risks. Broader preventative strategies such as reducing isolation, encouraging relationships and community involvement, supporting advocacy for people living with disability and making communities more accessible and inclusive will have greater impact in the longer term than reporting and corrective actions.

We recommend the Senate Standing Committee on Community Affairs, as part of a range of safeguarding initiatives:

- Implement a nationally consistent and contemporary approach to preventing and responding to abuse through a framework such as the *Model of Citizenship Support*,¹ which can be used to plan both whole-system measures and individual supports in ways where there is systematic attention to the person’s humanity, value and belonging.
- Within this framework, co-design with people living with disability and their families, a coherent, rights-based, multi-faceted system for preventing and responding to abuse, and ensure mechanisms are in place within such a system so that it has authentic powers to take action.
- Endorse an Australia-wide, zero-tolerance approach to violence against, and the abuse and neglect of, people living with disability, such as is identified in the National Disability Services Zero Tolerance Initiative.²
- Strengthen the language in the National Standards for Disability Services to endorse a zero-tolerance approach.
- Explore pathways to contemporary housing models which enable individuals to have greater connection to the community; consequently improving the natural safeguards which come with authentic connection, and reducing the risk of violence, abuse and neglect.
- Consider the SA Disability Justice Plan as a possible blueprint to be implemented across all Australian jurisdictions to:
 - Uphold, protect and promote the rights of people living with disability
 - Support vulnerable victims and witnesses in the giving of evidence
 - Support people living with disability who are accused or convicted of a crime
 - Continuously monitor and improve performance.

¹ Williams, R. (2013), *Model of Citizenship Support: 2nd edition*, Julia Farr Association Inc., Unley South Australia

² National Disability Services (2015), *Zero Tolerance Framework*, <http://www.nds.org.au/projects/article/194>

- Endorse strategies from the 2013 National Symposium on Violence against Women and Girls with Disabilities as a matter of urgency, to develop capacity building or peer support programs for women living with disability in institutions, and ratify Commonwealth/State/Territory legislation to recognise all forms of violence against women and girls perpetrated in all settings, including institutional and congregate care settings.
- Consider implementing a national mandatory system for reporting abuse of people living with certain types of disability as one element in a comprehensive range of measures.

2. Introduction

2.1. JFA Purple Orange

JFA Purple Orange applauds the Senate Standing Committee on Community Affairs' commitment to achieving appropriate and just outcomes for people living with disability, and appreciates the opportunity to provide a submission to the Inquiry on *'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.'*

JFA Purple Orange is the social policy agency of the Julia Farr group, a trio of social profit, non-government organisations based in South Australia, working to improve the life chances of people living with disability. The Julia Farr group (JFA Purple Orange, Julia Farr Housing Association, and the Julia Farr Trust and Julia Farr MS McLeod Benevolent Funds) and its predecessor organisations have been involved with the disability community, older people and other vulnerable groups for more than 130 years. We are an independent, non-government organisation that fosters innovation, shares useful information, and promotes policy and practice that support and improve the life chances of people living with disability.

JFA Purple Orange is not a service provider – we deliver research, evaluation and information services anchored upon the stories and experiences shared by people with a lived experience of disability and others in their lives.

2.2. International and National Contexts

The matters outlined in the Senate Inquiry Terms of Reference highlight some of the key factors in ensuring people living with disability live a life free from exploitation, violence and abuse as stipulated in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), ratified by the Australian Government and endorsed by the National Disability Strategy 2010-2020.

2.2.1. The United Nations Convention on the Rights of Persons with Disabilities

There is national recognition, through the ratification of the UNCRPD by Australia in July 2008, that all people living with disability have the right to live their life free from any form of abuse or restrictive practices. Article 16³ states:

1. States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.
2. States Parties shall also take all appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring, inter alia, appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers, including through the provision of information and education on how to avoid, recognize and report instances of exploitation, violence and abuse. States Parties shall ensure that protection services are age-, gender- and disability-sensitive.

³ United Nations, (2006), *Convention on the Rights of Persons with Disabilities*
<http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>

3. In order to prevent the occurrence of all forms of exploitation, violence and abuse, States Parties shall ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities.
4. States Parties shall take all appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, including through the provision of protection services. Such recovery and reintegration shall take place in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person and takes into account gender- and age-specific needs.
5. States Parties shall put in place effective legislation and policies, including women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted.

2.2.2. The National Disability Strategy

The National Disability Strategy 2010-2020 highlights issues relating to rights, protection, justice and legislation in Policy Area 2 which undertakes that “people with disability [are to] be safe from violence, exploitation and neglect.”⁴ Research indicates that internationally the situation is no different to that in Australia with violence, abuse and neglect being perpetrated against adults living with disability, who are at an increased risk of violence compared with non-disabled adults. This is compounded by general underreporting of abuse and maltreatment of adults. A 2012 World Health Organisation report on the prevalence and risk of violence against adults living with disability states that, internationally:

People with disabilities seem to be at an increased risk of interpersonal violence because of several factors: exclusion from education and employment, the need for personal assistance with daily living, reduced physical and emotional defences, communication barriers that hamper the reporting of violence, societal stigma, and discrimination.⁵

These barriers likewise occur in Australia. Similarly in Canada, the key factors in abuse and neglect of people living with disability are seen to be “... isolation, powerlessness, discrimination, poverty and social exclusion.”⁶

The importance of effecting social change and an emphasis on inclusion, rather than relying on a reactive, corrective framework to respond to violence, abuse and neglect is observed internationally.

⁴ Commonwealth of Australia (2011), *National Disability Strategy 2010-2020* pp. 36, 38.

⁵ Hughes, K., Bellis, M., Jones, L., Wood, S., Bates, G., Eckley, L., McCoy, E., Mikton, C., Shakespeare, T. and Officer, A. (2012), *Prevalence and risk of violence against adults with disabilities: a systematic review and meta-analysis of observational studies*. Lancet 2012; doi:10.1016/S0410-6736(11)61851-5.

⁶ Community Living Ontario (undated), *Adults who are Vulnerable to Abuse and Neglect: Discussion Paper*

For example, the UK Social Care Institute for Excellence, which works to identify and embed good practice in social service provision, found that in common with Australia:

Prevention of abuse has not always been high on the adult safeguarding agenda, but there is growing consensus about the importance of everyone with an interest in adult care services making efforts to prevent abuse of vulnerable adults ... Prevention needs to take place in the context of person-centred support and personalisation, with individuals empowered to make choices and supported to manage risks.⁷

Similarly, a Canadian report notes the: “Most reliable protections from harm and abuse happening to people who have a disability involve broader actions to effect social change.”⁸

JFA Purple Orange’s submission to the Senate Standing Committee on Community Affairs endorses the UNCRPW and National Disability Strategy. We provide evidence below to support the human rights imperative of preventing violence, neglect and all forms of abuse inflicted upon people living with disability, regardless of their place of residence. We highlight that each individual must have power, choice and control over their own lives, within an inclusive society to effect any real and sustainable change.

⁷ Faulkner, A. & Sweeney, A. (2014), *Prevention in Adult Safeguarding*, Social Care Institute for Excellence, UK.

⁸ Community Living Ontario (undated), *Adults who are Vulnerable to Abuse and Neglect: Discussion Paper*

2.3. Key Principles

The work of JFA Purple Orange is anchored on the principles of Personhood and Citizenship and is guided by human rights values and social inclusion. Every human being seeks to build a good life for themselves. As set out in our *Model of Citizenship Support*,⁹ a good life might be characterised by the presence of:

- Authorship of an individual's own life, termed Personhood (often described as control and choice)
- Having valued roles in community life and the economy, termed Citizenship (often described as inclusion).

A good life largely depends on the availability of life chances – the assets and opportunities available to a person. Unlike citizenship, Citizenship is a dynamic experience: it can rise and fall depending on a person's circumstances.

The *Model of Citizenship Support* refers to an intentional set of arrangements that authentically advance a person's life chances towards Citizenship, in keeping with each person's lifestyle choices. The Model provides a comprehensive contextual framework for organising policy and practice in support of people living with disability. It asserts that our life chances comprise four different, but interrelated, types of assets we can call upon, termed the Four Capitals.

These are: Personal Capital (how the person sees themselves in a positive way), Knowledge Capital (what the person knows and can do), Material Capital (the tangible things in our lives) and Social Capital (having people in our lives who we know and know us).

⁹ Williams, R. (2013), *Model of Citizenship Support: 2nd edition*, Julia Farr Association Inc, Unley South Australia

These apply to any person and can help explain what might be helpful for someone to build a good life for themselves.

The work of JFA Purple Orange highlights the risk of abuse and neglect can be reduced significantly by building the life chances of people living with disability, particularly through working within a philosophical framework such as the *Model of Citizenship Support*. A schematic and systemic response must include measures that positively build a person's capacity and maximise the good in a person's life rather than focussing on preventing bad things happening. Any measures to reduce the risk of abuse must not, as a consequence, reduce access to life chances or impact an individual's authorship of their own life. It must not be about "over-protective paternalism or risk-averse practice. Instead, the prevention of abuse should occur in the context of person-centred support and personalisation, with individuals empowered to make choices and supported to manage risks."¹⁰ Risk reduction measures must in fact be part of authentic plan to build life chances for individuals, for example, encouraging an individual to explore connections to the local community through an area of interest. This has the added benefit of increasing Citizenship while connecting the individual to others who may look out for their wellbeing.

Prevention of abuse must have at its foundation genuine conversations with people who may be at risk, and with those who have experienced abuse; to enable individuals to develop control and choice, genuine relationships with people who are not paid to be in their life, and connections to their community of choice.

¹⁰ Faulkner, A. and Sweeney, A. (2014), *Prevention in Adult Safeguarding*, Social Care Institute for Excellence, UK.

People in institutional care are much more likely to miss out on meaningful natural relationships that come from being part of the community and being regarded as a fellow citizen. The importance of developing positive life chances cannot be overstated in relation to safeguarding people living with disability from abuse.

Wherever violence, abuse or neglect occurs, basic human rights are violated, and an individual's Personhood and Citizenship are diminished. Governments must work with individuals with a lived experience of disability and with the broader community to ensure that people living with disability are free from the potential of abuse, and they are able to have the choice, control and valued roles that the majority of the community take for granted.

3. Our Approach to this Submission

Our submission focuses on the values, matters of concern and experiences of JFA Purple Orange drawn from discussions with people living with disability who have an understanding of the significant impact of violence, abuse or neglect. We have included their reflections in our submission, along with suggested safeguarding frameworks and recommendations for the Senate Community Affairs Committee to consider.

The issues of primary interest to JFA Purple Orange are those outlined in eight of the Inquiry's Terms of Reference; each of these are addressed in detail in the following pages.

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

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

3.1. Definitions

For the purpose of our submission, we have defined:

- ‘Institutional and residential settings’ as large congregate facilities, boarding houses, supported residential facilities, small group homes (three or four individuals sharing one house in the community), and large group homes (multiple dwellings on one site, each with a number of individuals sharing a house) respite facilities, residential aged care facilities and hostels.
- ‘Violence, abuse and neglect’ as including physical abuse, sexual abuse, emotional abuse, financial abuse and exploitation, neglect, restrictive practices and systemic abuse.

3.2. Terms of Reference (a) the experiences of people directly or indirectly affected by violence, abuse and neglect perpetrated against people with disability in institutional and residential contexts

Evidence has shown that people living with disability are at a far greater risk of violence than others in the population and that this violence often goes unrecognised or unaddressed. For example, 18 per cent of people living with disability report being victims of physical or threatened violence compared to 10 per cent of non-disabled people; and people living with intellectual disability are ten times more likely to have experienced violence than non-disabled people.¹¹ It is also recognised that the available statistics are not likely to be a true representation of what is actually occurring, due to the “obstacles experienced by people with a disability to reporting abuse, such as fear of losing services or not being believed, reliance on assistance for day to day support, language or communication difficulties and lack of awareness of rights and what constitutes abuse.”¹²

Australian studies indicate the likelihood of victimisation differs according to an individual’s living arrangements, such that people living with intellectual disability in shared residential care or institutional settings are most vulnerable to abuse. Furthermore, where the person experiencing abuse is dependent on a carer who is perpetrating abuse, the capacity to report is severely restricted.¹³

JFA Purple Orange’s experience highlights that institutionalised residential settings may increase the chances of people being abused because they make people invisible to the

¹¹ Frohmader, C. and Sands, T (2014), *Fact Sheet: Violence Against People With Disabilities in Institutions and Residential Settings*, Women with Disabilities Australia and People with Disability.

¹² Coulson Barr, L. (2012), *Learning from Complaints, Occasional Paper No.1, Safeguarding People's Right to be Free from Abuse*. Victorian Disability Services Commissioner

¹³ Murray, S. and Powell, A. (2008), *Sexual assault and adults with a disability: Enabling recognition, disclosure and a just response*. Australian Institute for Family Studies and the Australian Centre for the Study of Sexual Assault, Issues 9: 3-4.

community. As outlined earlier, JFA Purple Orange does not consider institutional services to only be large congregate accommodation and day services; they are also smaller services such as four person group homes, supported residential facilities, respite facilities, boarding houses, residential aged care facilities and hostels. What makes these services institutional is their practice, where vulnerable people receive services largely away from the eyes of the community, and where the main people in their lives are paid to be there. Violence, abuse and neglect in such settings are difficult to detect, report, investigate and prosecute.

As Silvana Gant, President and Convenor of Adelaide People First (a volunteer-based systems advocacy group run by people with a lived experience of disability) states:

We must understand as a society, from the community level up, an institution is not just a place, it's the way people think. We must always challenge the low expectations. When people living with a disability are kept dependent and isolated from having meaningful connection and a valued life with family, friends and community, we are made more vulnerable to an institutional culture of violence. We must shine a light of truth into what is happening in all institutions where people living with disability are made dependent for our basic life needs and vulnerable to violence, abuse, neglect, exploitation and discrimination.¹⁴

Changing the nature of institutionalised residential settings is critical to combatting the ongoing violence, abuse and neglect experienced by some people living with disability. We have suggested a range of best practice options in the following sections.

¹⁴ Gant, S. (2014), *Adelaide People First Media Release, 15 Dec 2014*. <http://www.purpleorange.org.au/news-links/external-news/adelaide-people-first-media-re/>

3.3. TOR (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

The impact of violence, abuse and neglect on people living with disability can be intense, overwhelming and long-lasting, particularly where the abuse is perpetrated over an extended period of time. The adverse impacts affect not only the victim, but also their families, other service-users and the staff who genuinely have the wellbeing of people with disability at the forefront of their practice.

Violence and abuse are born out of power and control over another person, typically in relationships where a person has power over another person due to a greater vulnerability. JFA Purple Orange's work with people living with disability and their families highlights the extreme power inequalities which exist between staff and residents in institutions, particularly when people are reliant on staff to assist with personal care, meal times, transport, and communication. JFA Purple Orange has been told of emotionally abusive situations in some institutional settings arising from lack of privacy. For example, some settings have no doors on bathrooms, and some women have no choice about being showered in men's bathrooms as staff do not have the time to wait until the women's bathroom is available.¹⁵

Even where people living in institutional or residential care have personal relationships outside the care situation, with others who have genuine regard for them, the abusive relationship may not be apparent to an external eye, as perpetrators are often able to present themselves in a credible way to other people.

¹⁵ JFA Purple Orange (2015), interview commentary

3.3.1. Impact of gender

Women With Disabilities Australia (WWDA) outline that the experience of violence is intensified in frequency, extent and nature when gender and disability intersect. They comment that in Australia, women and girls living with disability experience higher levels of violence compared to non-disabled women and girls, and they are more likely to experience violence in residential and institutional settings.¹⁶

This is due, in part, to the impact of power imbalance for women living with disability as “in general women with disabilities are perceived as being powerless. Therefore, when women with disabilities form relationships with people without disabilities, they are likely to find themselves in relationships where the other person has and maintains the power.”¹⁷

Women living with disability have usually experienced a cycle of negativity¹⁸ in their lives; with a young girl living with disability continually hearing negative messages about herself, her ability and her future potential. This cycle of negativity feeds into the relationship power imbalance; “this negativity seeps through to the child’s core and leads to them having a very low opinion of themselves. They may see themselves only as useless and a burden.”¹⁹

JFA Purple Orange’s discussions with women with a lived experience of disability highlighted that women living with disability consider themselves a woman first, who happens to live with disability. They report that when abuse occurs, gender tends to be seen as a secondary issue, whereas the power imbalance caused by the intersection of gender and disability is central to the abuse occurring.

¹⁶ Dowse, L., Soldatic, K., Didi, A., Frohmader, C. and van Toorn, G. (2013), *Stop the Violence: Addressing Violence Against Women and Girls with Disabilities in Australia. Background Paper*. Hobart: Women with Disabilities Australia.

¹⁷ Charlesworth, M. (2008), *“The Price We Pay” Women, Disability and Emotion*, Honours Thesis

¹⁸ Lee, G. (2004), *Eliminate the Negative, Accentuate the Positive*, Physical Disability Council Conference. Fremantle, Perth. Unpublished; referenced in Charlesworth, M. (2008), *“The Price We Pay” Women, Disability and Emotion*, Honours Thesis

¹⁹ Lee, G. (1998), *The Cycle of Negativity*, unpublished

As described by Charlesworth (2008):

...[as] many women use personal assistants to help them with everyday living activities – which are mostly conducted in privacy – there is a high probability that abuse can occur. These pervasive forms of violence that can be perpetrated against women with disabilities can be at the hand of support workers or carers and include withholding devices such as mobility and communication devices; leaving a woman’s electric wheelchair out of reach or unlocked (so that the chair cannot move); and denying the woman medical care and medication. Violence may also occur in the form of intimidation which can include the support worker or carer yelling, punching walls, and using verbal threats.²⁰

Although women living with disability in institutional settings are at particular and significant risk of violence, abuse, neglect and exploitation, such violence is typically minimised through service responses that identify the violence as a “workplace issue to be addressed, rather than a human rights violation and potential criminal act.”²¹

The *National Plan to Reduce Violence Against Women and Their Children* (2010),²² an initiative of the Council of Australian Governments, does not explicitly include the issue of gender-based violence experienced by women living with disability in institutions. It does however recognise the need for improved services for women living with disability.

²⁰ Charlesworth, M. (2008), *“The Price We Pay” Women, Disability and Emotion*, Honours Thesis

²¹ Frohmader, C., Dowse, L. and Didi, A. (2015), *Preventing Violence against Women and Girls with Disabilities: Integrating A Human Rights Perspective*, Women with Disabilities Australia

²² Council of Australian Governments (2010), *National Plan to Reduce Violence Against Women and their Children*. Commonwealth of Australia

As part of the First Action Plan (2010-2013) under the *National Plan to Reduce Violence Against Women and Their Children*, WWDA was funded to investigate and promote ways to improve access and service responses for women and girls living with disability experiencing, or at risk of, violence. A National Symposium on Violence against Women and Girls with Disabilities was held in 2013. Critically, the report of the symposium acknowledged that “violence perpetrated against women and girls with disabilities in institutions is rarely characterised as domestic violence and rarely are domestic violence related interventions deployed to deal with this type of violence.”²³

The Symposium recommended capacity building programs for women living with disability in institutions, along with reviews of Commonwealth/State/Territory legislation to recognise all forms of violence against women and girls perpetrated in all settings, including institutional and congregate care settings. The second iteration of the Action Plan (2013-2016)²⁴ focusses in part on deepening the understanding of the experiences of violence faced by women living with disability, but does not specifically endorse the recommendations from the WWDA Symposium. JFA Purple orange recommends the Senate Standing Committee on Community Affairs endorse these strategies as a matter of urgency.

3.3.2. Abuse outside institutional settings

It is important to recognise that abuse can occur anywhere; it is not specific to institutional or residential settings. For many people living with a disability in the community, primary support is provided by family members, and many families undertake a significant caring role when supporting a family member living with disability. The pressure of this can be aggravated by difficulties in accessing information and support, and mainstream opportunities and amenities that many people take for granted.

²³ Women with Disabilities Australia (2013), *National Symposium on Violence against Women and Girls with Disabilities: Report of the Proceedings and Outcomes*.

²⁴ Council of Australian Governments (2013), *The National Plan to Reduce Violence Against Women and Their Children. Second Action Plan 2013-2016 - Moving Ahead*, Commonwealth of Australia

JFA Purple Orange's 2011 *Tellus* Survey²⁵ showed many families are under great personal pressure as a result of the informal support they give to family members living with disability. The survey showed eight out of ten families say that providing support to a family member comes at a significant – and often devastating – cost in terms of mental and physical health, relationships and opportunity.

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

The role of a social policy agency such as JFA Purple Orange is in advocating for people living with disability, and in influencing Government and organisational policy and practices so that people living with disability get a fair go at everything life has to offer. However, one of the main challenges of formal advocacy includes difficulties accessing service settings to observe what is occurring on a day to day basis. Initiatives such as the Community Visitor Scheme allow independent volunteers to visit and inspect disability accommodation and Supported Residential Facilities to ensure residents are being treated with dignity and respect, and that services are responsive and appropriate²⁶ but these visitors cannot have in-depth knowledge of what is happening for each resident in every residential or institutional setting in Australia.

²⁵ The 2011 *Tellus* survey was designed by the Julia Farr Association to discover the deeper issues for people living with disability and their families, issues that are not apparent via census data or other standard data-gathering methods. The survey was conducted over a period of 15 months, and 886 people participated nationally.

²⁶ SA Community Visitors Scheme (2015), *Community Visitors Scheme brochure*
<https://www.sa.gov.au/topics/citizens-and-your-rights/feedback-and-complaints/community-visitor-scheme>

Much of the advocacy funding is directed towards reactive advocacy services, e.g. responding to complaints. This however misses the mark for people who arguably are at the greatest risk of abuse because the disability they live with (and corresponding service setting) mean they are far less able to raise a complaint to an independent party. A more proactive independent form of advocacy is required, particularly for people living with intellectual disability or cognitive impairment. As Adelaide People First states: "Independent advocacy support has a vital safeguarding and accountability role in the lives of people living with intellectual disability, whose lives are controlled by human services."²⁷

In relation to informal disability advocacy, one of the main challenges is that many people living with disability receive their services away from the gaze of the wider community and away from connections with that community. The nature of residential settings is such that they are:

Places/spaces that, to this day, carry the hallmarks of violence, oppression and trauma. Places that, while looking different, even homely, leave people stranded from community life and those who work with them anxious and prone to authoritarianism in order to deal with the stresses of incompatible group living, poor skills, low support from management and forgotten values and restricted vision.²⁸

²⁷ Adelaide People First (2014), *2014 South Australian State Election Bulletin*

²⁸ Hallahan, L., (2012), *Towards quality and safety in disability services: Confronting the 'corruption of care'*, SA Health and Community Services Complaints Commissioner

Many people living with disability only have people in their lives who are paid to be there; potentially it could be these people who are perpetrating the violence or abuse. Without an informal network of support around that person it is highly unlikely that their voice will be heard. Consequently, there is no real opportunity for informal advocacy to emerge within such institutions.

3.5. TOR (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

People living with disability face significant barriers to reporting abuse:

A consistent theme is the finding that people with a disability are much more likely to experience abuse, including physical and sexual assault, than the general population. At the same time, it is widely recognised in the literature that the available data is unlikely to give the true picture of the level of risk and prevalence of abuse, due to the obstacles experienced by people with a disability to reporting abuse, such as fear of losing services or not being believed, reliance on assistance for day to day support, language or communication difficulties and lack of awareness of rights and what constitutes abuse.²⁹

²⁹ Coulson Barr, L. (2012), *Learning from Complaints, Occasional Paper No.1, Safeguarding People's Right to be Free from Abuse*. Victorian Disability Services Commissioner

The South Australian Health and Community Services Complaints Commissioner (SAHCSCC) identifies additional barriers to reporting, investigating and responding to violence and abuse,³⁰ including:

- Impaired communication capacity
- Fear
- Trauma which can contribute to silencing
- Voicelessness produced by being overwhelmed by their circumstances
- Stifled expectations leading to a normalisation of abuse
- No expectation of change and not being heard
- Fear of cost and retribution
- Worker uncertainty
- Social indifference.

Conversations conducted by JFA Purple Orange with people living with disability, as part of a regional conference circuit, confirmed these barriers. The Loop Conference³¹ explored the theme of ‘Why is it so hard to speak up and be heard?’ and heard from conference participants about the barriers that result in the disability community being a subdued voice.

³⁰ Hallahan, L., (2012), *Towards quality and safety in disability services: Confronting the ‘corruption of care’*, SA Health and Community Services Complaints Commissioner

³¹ Julia Farr Association (2007), *Why is it so hard to speak up and be heard? – Views from the Loop Conference 2007*.

Participants outlined general barriers to speaking up; many of these are also applicable in the under-reporting of abuse:

- Lack of information about systems
- Lack of confidence
- Fear of retribution
- Time and distance when living in country locations
- Attitudes and behaviours of others – not being taken seriously
- Unhelpful processes
- No collective voice
- System is not solution focussed.

It appears from participants' comments that current systems perpetuate marginalisation of people living with disability by creating a climate where people fear to raise their voice.

Fundamentally, people are at greater risk of abuse if they do not direct their own life, if they cannot communicate or are not listened to. Many people living with disability are unaware of their rights, and accept whatever support or service is provided regardless of whether it is suitable or satisfactory, because they fear the service may be withdrawn. The medical model of disability continues to describe people in terms of their 'inability' to achieve physical, intellectual or social milestones. This, in combination with the common media portrayal of people living with disability 'battling adversity', reinforces the need for education and peer support to enable individuals to self-determine what happens in their lives, and in particular, how their care and support needs are met.

JFA Purple Orange’s discussion with people with a lived experience of disability highlights the importance of education in empowering individuals to know when abuse is occurring. Fundamentally, a person needs to know that what is occurring is wrong, before they know to report it: “When you have learnt to value yourself, you are more able to stand up for yourself. Some women don’t even know what violence is – not because it’s not happening – but because it’s always there, it’s a normal part of life.”³²

Some individuals who have lived with disability from birth or childhood have received little, if any, sexual education, as noted at a 2014 conference for young people with disability:

There are many stereotypes and myths relating to people living with disability and relationships, for example, that men and women living with disability do not have sex, are asexual, are not sexually attractive or that a person does not need sexual health education. These community misconceptions are a major issue for people living with disability.³³

“Sex education is really important. Students [living with disability] are so often taken out of things such as PE lessons and sex education without being consulted. We should all have the option and know what is available.”³⁴

With education from a young age, such acceptance of abuse as ‘normal’ will no longer occur, however, this may take a whole generation for change to be truly effected.

³² JFA Purple Orange (2015), interview quote

³³ Julia Farr Association (2014), *Julia Farr Youth Conference April 2014 Report*

³⁴ Julia Farr Association (2014), *Julia Farr Youth Conference April 2014 Report*

JFA Purple Orange recommends the development of a coherent, rights-based, multifeatured system for preventing and responding to abuse which is accessible and is based on empowering the individual to instigate an investigation into any adverse treatment.

3.5.1. Criminal justice system

Significant barriers to reporting, investigating and responding to allegations of abuse occur within the various criminal justice systems in Australia. As outlined by the Australian Human Rights Commission:

People with disabilities do not enjoy equality before the law when they come into contact with the criminal justice system in Australia. Whether a person with disability is the victim of a crime, accused of a crime or a witness, they are at increased risk of being disrespected and disbelieved. If a victim, their disability may be seen to mitigate the offender's guilt; if a perpetrator, their disability makes incarceration more likely. Fundamental human rights that we all expect to enjoy are at stake.³⁵

In South Australia, significant work has been undertaken by the Attorney-General's Department to make the criminal justice system more accessible and responsive to the needs of people living with disability, with the development of the *Disability Justice Plan 2014-2017*.

³⁵ Australian Human Rights Commission (2014), *Equal before the Law: Towards Disability Justice Strategies*, Australian Human Rights Commission

According to the Foreword by the SA Attorney-General:

The Plan has been developed in recognition of the fact that some people with disability are more vulnerable to victimisation and abuse in the community, particularly those with cognitive and/or intellectual disability. The Disability Justice Plan brings together some significant changes to the law that will improve the way evidence is taken and presented in court, along with the necessary underlying cultural changes to the way agencies go about their business that will make programs and services more inclusive.³⁶

Although developed for the SA jurisdiction, the *Disability Justice Plan* would provide a sound basis for all Australian jurisdictions to standardise criminal justice support for people living with disability, regardless of where they are in Australia. JFA Purple Orange recommends there be consideration of implementing a similar Justice Plan across all Australian jurisdictions under the four key themes of:

- Upholding, protecting and promoting the rights of people with disability
- Supporting vulnerable victims and witnesses in the giving of evidence
- Supporting people with disability accused or convicted of a crime
- Continuously monitoring and improving performance.

³⁶ SA Attorney-General's Department (2014), *Disability Justice Plan 2014-2017*, SA Government.

3.6. TOR (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

3.6.1. Prevention

The best option to effectively protect people living with disability from violence, abuse and neglect in institutional settings is to dramatically change the nature of the setting in which such abuse has occurred in the past. Institutions and residential facilities fundamentally segregate people living with disability from the community. They provide an impoverished life, compared to the life of non-disabled people. An institutional lifestyle has an artificial structure and routine to the day; people generally experience a reduction in social contacts; and have limited choice and control in their lives.

Australia needs a shift in the types of services commissioned away from services that routinely put vulnerable people into groups where the main people in their lives are those paid to be there. A shift in service type to more contemporary models would support a genuine focus on supporting people as visible and contributing citizens in community life, where the range of relationships extend well beyond paid staff. A significant element of a shift to more contemporary models is the principle of separating housing from personal support arrangements. This allows people to change either their housing or personal support without affecting the other. Being both landlord and support service provider is a clear conflict of interest, and “increases the vulnerability of the people receiving and dependent on grouped models of service to abuse, neglect, discrimination and exploitation, especially when a problem arises with the support service or landlord.”³⁷

³⁷ Adelaide People First (2014), *2014 South Australian State Election Bulletin*

JFA Purple Orange made a submission to the recent 2015 Senate Standing Committee on Community Affairs' Inquiry on "The adequacy of existing residential care arrangements for young people with severe physical, mental or intellectual disabilities in Australia" which outlined a number of contemporary housing models which by design would be less likely to be the setting for systemic abuse. Suggested models include:

- Living with family with appropriate building modifications
- Co-tenancy with friends or flatmates in private rental or affordable housing
- Living alone with support as required in private rental or affordable housing
- Home-share options where a person living with disability shares accommodation with a non-disabled person (often a student) for reduced or no rent in exchange for support around the home
- Attendant care – individual dwellings peppered within a suburb who use the same support
- Mini-cluster housing – two or three units on one site with support as required.³⁸

JFA Purple Orange recommends that pathways to best practice contemporary models are explored to enable individuals to have genuine choice and control about their housing, which would in turn reduce the risk of violence, abuse and neglect.

³⁸ For more detail see JFA Purple Orange's submission (number 143) to the 2015 Senate Standing Committee on Community Affairs' Inquiry on *The adequacy of existing residential care arrangements for young people with severe physical, mental or intellectual disabilities in Australia*.

In addition to a change to the accommodation landscape for people living with disability, best practice systems for prevention of abuse must also be implemented. Experience in the United Kingdom identified by the Social Care Institute for Excellence (SCIE) indicates the “value of awareness raising about abuse within a service context lies in linking it with a zero tolerance policy on abuse and supportive policies and procedures to support whistle blowing.”³⁹

SCIE further identified key foundations for prevention and early intervention:

- people being informed of their rights to be free from abuse and supported to exercise these rights, including access to advocacy
- a well trained workforce operating in a culture of zero tolerance of abuse
- sound framework for confidentiality and information sharing across agencies
- good universal services, such as community safety services
- needs and risk assessments to inform people’s choices
- a range of options for support to keep safe from abuse tailored to people’s individual needs
- services that prioritise both safeguarding and independence
- public awareness of the issues.⁴⁰

Whatever initiatives are implemented to protect people living with disability from violence, abuse and neglect, they must include the key driver of an open organisational culture which is genuinely person-centred, and reinforced by a zero-tolerance approach to violence and abuse in all service contexts.

³⁹ Faulkner A. and Sweeney A. (2011), *Prevention in adult safeguarding* SCIE United Kingdom.

⁴⁰ Faulkner A. and Sweeney A. (2011), *Prevention in adult safeguarding* SCIE United Kingdom.

One such approach could be the adoption of a national scheme similar to the Victorian Disability Worker Exclusion Scheme.⁴¹ This initiative is designed to further protect the safety and wellbeing of people living with disability in residential care homes. The Scheme requires disability service providers (both government and non-government) to conduct an additional pre-employment check on employees, volunteers and students, prior to making an offer of employment. This check will require consulting the Disability Worker Exclusion Scheme unit to see if a person's name is on the list before permitting a person to work in a direct support role with service-users in a residential service.

Under the Victorian Scheme, a person will be considered for placement on the list in the following circumstances:

- (a) if they have been found guilty of any criminal offence, regardless of whether they are imprisoned, which involves bodily harm; involves violence or threats of violence; is of a sexual nature; involves dishonesty; or involves neglect of a person in their care, or
- (b) if their employment has previously been terminated for conduct which includes abusing a client, sexual misconduct with a client or otherwise placing a client at risk of serious harm, including where such conduct occurred in an area outside disability services, for example in a school or a nursing home, regardless of whether there was a criminal prosecution.⁴²

Such a system could be considered by the Senate to strengthen existing pre-employment screening processes on a national basis to better protect people living with disability.

⁴¹ Department Human Services Victoria (2015), *Disability Worker Exclusion Scheme*
<http://www.dhs.vic.gov.au/about-the-department/plans,-programs-and-projects/projects-and-initiatives/disability-services/disability-worker-exclusion-scheme>

⁴² Department Human Services, Victoria (2014), *Disability Worker Exclusion Scheme Management Instruction*, State Government Victoria

3.6.2. Reporting

There are stringent pieces of legislation which aim to protect children and older people from forms of abuse; for example, each state and territory has an Act which governs the administration and operation of child protection and mandated notification requirements; for older Australians, the Commonwealth Aged Care Act (1997) provides protection for adults living in residential aged care facilities. However there are few legislative bases for protection from abuse of adults living with disability. South Australian MLC, The Hon. Kelly Vincent, strongly advocates for the mandatory reporting of abuse of people living with certain disability, in addition to preventative safeguards in protecting people from abuse situations, to “lock the rights and inclusion of people with disability into our statute books.”⁴³ Ms Vincent states that protecting people with disability from abuse is not “an either (safeguards) or (mandatory reporting) situation, rather, mandatory reporting is an essential part of the jigsaw. We need safety nets at both ends of the spectrum.”⁴⁴

JFA Purple Orange supports this call for a legislative basis for protection from abuse, provided it is just one element in a comprehensive range of safeguarding measures. Legislation alone will not solve the human rights abuses occurring against people living with disability. For example, if an individual living with disability reports abuse by a service provider, it will be essential to have additional measures in place to ensure the safety of that person after a report is made, as the individual will still be reliant on that same service provider while investigations are being undertaken. The example of Winterbourne View Hospital, a congregate care home in the UK, described in Section 3.9 of this response, demonstrates how a mandatory reporting system does not guarantee people living in institutionalised settings will be protected from abuse.

⁴³ Vincent, K. (2013), *Media release: Disability Abuse – call for mandated reporting*

⁴⁴ Vincent, K. (2013), *Media release: Disability Abuse – call for mandated reporting*

If legislative measures are applied, a community awareness campaign would strengthen the community's understanding of the intent of the Act. One example is the "Act Against Harm"⁴⁵ campaign in Scotland implemented after the *Adult Support and Protection (Scotland) Act 2007* was introduced to identify, support and protect adults who may be at risk of harm or neglect, and who may not be able to protect themselves.

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

Systemic abuse is workforce or organisational practices that take away a person's independence and dignity. A range of risk factors for such abuse occur frequently in residential and institutional settings. Individuals at the greatest risk include people living with cognitive, communication and/or sensory impairments, particularly people who are non-verbal; people with high physical support needs and dependence; people who display behaviours of concern; and people without family, advocacy and community connections. Organisationally, the key risk factors are neglected physical environments; high staff turnover, stress and high use of agency or casual staff; isolated services, where unacceptable staff attitudes and practices can become normalised; poor management and lack of leadership; lack of policy awareness and skills of staff.⁴⁶

As highlighted in Section 3.6 of this response, it is critical to communicate unequivocal, zero-tolerance values with service-users, staff and families, and to develop a system which addresses some of the inherent risk factors.

⁴⁵ Scottish Government *Act Against Harm: Adult Support and protection*. <http://www.actagainstharm.org/>

⁴⁶ Coulson Barr, L. (2012), *Learning from Complaints, Occasional Paper No.1, Safeguarding People's Right to be Free from Abuse*. Victorian Disability Services Commissioner.

Elements of such a system may include planning, recruitment, induction, support (including staff development, complaints, disciplinary, grievance, and whistleblowing); and policies which support individual development, quality of life, choice and control. Workforce development and training, strong interagency relationships and communication and a culture of review and innovation are all measures which will strengthen the workplace environment.

The current National Standards for Disability Services⁴⁷ use fairly mild language to describe abuse such as “acknowledge the risks of harm, neglect, abuse or violence which some people with disability may face when using services or supports” and “emphasise the importance of freedom from abuse”. Strengthening the language used in the National Standards for Disability Services to endorse a zero-tolerance approach would signal a nationally consistent safeguarding response and provide absolute clarity about why such practices are unacceptable.

The design, operation and oversight of organisational practices will be strengthened where they are co-designed with people living with disability and their family. Co-design is grounded on the premise that if the intended beneficiaries of a system are involved in its design, that design is likely to be more effective in its benefits. A focus on service user experience can provide valuable insights into opinions, actions, needs and behaviours; and develops richer and more effective material.

One example of such an approach is the Zero Tolerance initiative led by National Disability Services, in partnership with the disability sector, which is developing a framework to improve safeguards for people living with disability.

⁴⁷ Department Social Services (2013), National Standards for Disability Services
https://www.dss.gov.au/sites/default/files/documents/12_2013/nsds_web.pdf

It aims to address systemic workforce issues by developing practical tools and resources for disability service providers to improve prevention, early intervention and responses to abuse, neglect and violence towards people living with disability. The initiative aims to provide an:

evidence-based, nationally consistent and contemporary approach to preventing and responding to abuse which can impact on organisational cultures, improve practice, and influence the development of safeguarding mechanisms emerging from the National Disability Insurance Scheme.⁴⁸

JFA Purple Orange supports such an approach, and recommends the Senate Standing Committee on Community Affairs endorse it as a national strategy as part of a range of safeguarding initiatives.

⁴⁸ National Disability Services (2015), *Zero Tolerance Framework*, <http://www.nds.org.au/projects/article/194>

3.8. TOR (I) 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

The introduction of the NDIS is a critical point for violence prevention and response. As the uniform disability service for people with disabilities across Australia, this program has the power to influence good practice in preventing and identifying violence, abuse and exploitation. Cross-sectoral cooperation and referral pathways are essential and it is vital that the new NDIS workforce is well trained in applying the principles of good practice learnt from other sectors.⁴⁹

The introduction of the NDIS provides an opportunity to co-design innovative service provision options with people living with disability. As the Productivity Commission notes in its *Report into Disability Care and Support*; financial, psychological, physical and sexual abuse each decreased under international examples of individualised funding.⁵⁰ To ensure Australia follows suit in its implementation of individualised funding, it is imperative to have safeguarding initiatives in place as part of the rollout of the NDIS. JFA Purple Orange notes that currently the NDIS is undertaking a consultation process for the NDIS Quality and Safeguarding Framework, and supports the suggested broad safeguarding structure covering (i) developmental; ii) preventative and (iii) corrective types of safeguarding.

⁴⁹ Woodlock, D., Healey, L., Howe, K., McGuire, M., Geddes, V. and Granek, S. (2014), *Voices Against Violence Paper One: Summary Report and Recommendations* (Women with Disabilities Victoria, Office of the Public Advocate and Domestic Violence Resource Centre Victoria).

⁵⁰ Productivity Commission (2011), *Disability Care and Support: Executive Summary*, Report no. 54, Canberra.

The NDIS offers the promise of more choice and control for people living with disability. This has to include genuine alternatives to institutional and residential settings, such that all services can be measured and held accountable for their capacity to build authentic visibility and connection for people living with disability. The NDIS yardstick of ‘reasonable and necessary support’ should rightly be in the context of a safeguarded ‘fair go’ at what life has to offer.

This presents a real opportunity to redesign away from ‘grouping’ or ‘isolating’ to genuine person-centred services and an investment in capacity building across communities, organisations and mainstream service delivery, to influence attitudes and practices that can lead to greater inclusion and engagement of people living with disability.

3.9. TOR (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

“Safeguarding refers to the range of activities that aim to minimise the risk to harm for a person with disability and protect their intrinsic human rights. Safeguarding activities seek to support and empower people to exercise choice and control over their lives.”⁵¹ However, despite many decades of abuse directed towards people living with disability, there is still no effective safeguards system in place that offers the protection people deserve.

It is critical to employ a range of safeguards, both formal and informal, as no single safeguarding mechanism will, in and of, itself be sufficient to eliminate the risk of abuse. Formal safeguards are those implemented by governments or community-based organisations.

⁵¹ SA Department Communities and Social Inclusion, (2013), *Safeguarding People with Disability Overarching Policy*

Informal safeguards are those that may be quite intentional but occur outside of formal organisations. These could include family advocacy, friends, and positive community attitudes towards social inclusion.

Much of the literature on prevention of abuse refers to the need for strategies to consist of three levels; primary (developmental), secondary (preventative) and tertiary (corrective) intervention. While the definitions can vary, the aims of these different levels of intervention tend to be described in the following way:

A systemic approach to safeguarding people with disability should include a coherent mix of mechanisms ranging from developmental (training and awareness) to the preventative (good policy and practice) to the corrective (investigation, advocacy and enforcement).⁵²

In JFA Purple Orange's experience, people in institutional care are much more likely to miss out on meaningful natural relationships that come from being part of the community, and which can safeguard against neglect and abuse. International experience shows that it is important to consider introducing safeguards that support people living with disability to actively connect with their community and achieve Citizenship as: "People who are fully included and valued as citizens, neighbours, and friends are less vulnerable. Their well-being is tied to their connections and participation in community, not just the availability of funding and paid support."⁵³

⁵² South Australian Social Inclusion Board, (2011), *Strong Voices. A Blueprint to Enhance Life and Claim the Rights of People with Disability in South Australia*, p. 50.

⁵³ Community Living British Columbia (2009), *Addressing personal vulnerability through planning*, Community Living British Columbia, Vancouver, British Columbia.

One example of developing connections to the community is that of the Circles Initiative, a program that works with people living with disability who have no one to "look out" for them. The Circles Initiative intentionally invites people to come together and support a person living with disability for the purposes of protecting their interests into the future and supporting them to make decisions about their lives. People who step forward into the circle might be friends of family, friends of the individual, people who support the person, outsiders who have been identified as interested in being involved in the person's life.⁵⁴

For people who have no one except paid service workers in their lives, an effective circle can hold services accountable for their support to the person. Key benefits include:

- People living with disability being central to all discussions and activities
- Increased numbers of people in the life of each person who were not paid to be there
- Increased number of new, positive roles that people held
- Expanded social opportunities for people living with disability.

It is through the types of natural support such as a neighbour, employee, club member or fellow citizen that vulnerable people become more visible, more involved, and genuinely belong in community life. Visibility and connection offer a far stronger natural safeguard against neglect and abuse than shutting people away in congregate settings.

⁵⁴ Community Living Project SA (2014), *Circles Initiative*, <http://clp-sa.org.au/content/circles-initiative>

The more our communities offer natural supports, the less chance violence, abuse and neglect will happen.

While there is no excuse for any agency failing to take action on concerns about the possibility or incidence of neglect or abuse in its own services, attempted remedies such as complaints mechanisms, community visitor schemes and mandatory reporting will not fix the problem alone because they largely attend to the symptoms not the causes. One striking example of this is that of Winterbourne View Hospital, a congregate care home in the UK for adults living with intellectual disability and alleged challenging behaviour. Serious and systemic abuse occurred despite the presence of (and referrals by family to) the investigative powers of the Care Quality Commission and the mandatory reporting framework of the Independent Safeguarding Authority. The abuse was finally uncovered due to the actions of an undercover journalist with a camera, as part of the BBC Panorama series. Eleven defendants – nine support workers and two nurses – admitted 38 charges of either neglect or ill-treatment of five people living with intellectual disability. Six of the defendants were imprisoned as a result.

The UK Department of health investigation into the wide-ranging abuse commented:

The abuse revealed at Winterbourne View hospital was criminal. Staff whose job was to care for and help people instead routinely mistreated and abused them. Its management allowed a culture of abuse to flourish. Warning signs were not picked up or acted on by health or local authorities, and concerns raised by a whistleblower went unheeded. The fact that it took a television documentary to raise the alarm was itself a mark of failings in the system ... We should no more tolerate people with learning disabilities or autism being given the wrong care than we would accept the wrong treatment being given for cancer.⁵⁵

The issues of primary interest to JFA Purple Orange are those that address the balance between autonomy, choice and risk for people living with disability. Efforts to reduce risk of abuse must not reduce access to the autonomy, independence and quality of life for people living with disability. There is a difficult balancing act in ensuring protection, inclusion and personal autonomy while avoiding paternalism and inhibiting the right to choose.

⁵⁵ Department health (UK) (2012), *Transforming care: A national response to Winterbourne View Hospital. Department of Health Review: Final Report*

4. Conclusion

Any form of violence, abuse and neglect, in any setting, towards people living with disability is a violation of basic human rights. Governments, organisations and individuals must work together towards the prevention of all forms of abuse (including physical abuse, sexual abuse, emotional abuse, financial abuse and exploitation, neglect, restrictive practices and systemic abuse).

In developing preventative strategies, we must not lose sight of the causes of increased vulnerability to abuse and neglect. Prevention of abuse must occur in the context of person-centred support which increases Citizenhood, control and choice and supports an individual to manage risks. Broader preventative strategies such as reducing isolation, encouraging relationships and community involvement, support advocacy for people living with disability and making communities more accessible and inclusive will have greater impact in the longer term than reporting and corrective actions.

Safer environments are created by ensuring residents of institutional settings have connections with someone outside the service who can be alert to the possibility of abuse, as well as being a potential source of support and advocacy should abuse occur. Programs like the Community Visitors Program are identified as playing an important role in detecting and reporting suspected abuse, particularly for isolated individuals and services. The importance of service-users having a key support person outside the service is highlighted in international research, including the important role played by families in this regard.

Violence, abuse and neglect, has a fundamentally negative impact on an individual's life chances, reduces their Four Capitals (Personal, Knowledge, Material and Social), and decreases their Citizenhood. The *Model of Citizenhood Support* provides an opportunity for a safeguarding authority to frame and assess any service response in terms of its capacity to uphold and advance a person's life chances.

JFA Purple Orange believes abuse is much less likely to emerge if a person is supported in ways that enable the Four Capitals to be maintained. Upholding the *Model of Citizenship Support* as a philosophical base will increase an individual's life chances and should be the starting point for any conversation to facilitate choice, participation and autonomy.

Reducing the chance of violence, abuse and neglect is everyone's business.

5. Recommendations

We recommend the Senate Standing Committee on Community Affairs, as part of a raft of safeguarding initiatives:

- Implement a nationally consistent and contemporary approach to preventing and responding to abuse through a framework such as the *Model of Citizenship Support*,⁵⁶ which can be used to plan both whole-system measures and individual supports in ways where there is systematic attention to the person’s humanity, value and belonging.
- Within this framework, co-design with people living with disability and their families, a coherent, rights-based, multi-faceted system for preventing and responding to abuse, and ensure mechanisms are in place within such a system so that it has authentic powers to take action.
- Endorse an Australia-wide zero-tolerance approach to violence against, and the abuse and neglect of, people living with disability, such as is identified in the National Disability Services Zero Tolerance Initiative.⁵⁷
- Strengthen the language in the National Standards for Disability Services to endorse a zero-tolerance approach.
- Explore pathways to contemporary housing models which enable individuals to have greater connection to the community; consequently improving the natural safeguards which come with authentic connection, and reducing the risk of violence, abuse and neglect.

⁵⁶ Williams, R. (2013), *Model of Citizenship Support: 2nd edition*, Julia Farr Association Inc., Unley South Australia

⁵⁷ National Disability Services (2015), *Zero Tolerance Framework*, <http://www.nds.org.au/projects/article/194>

- Consider the SA Disability Justice Plan as a possible blueprint to be implemented across all Australian jurisdictions to:
 - Uphold, protect and promote the rights of people living with disability
 - Support vulnerable victims and witnesses in the giving of evidence
 - Support people living with disability accused or convicted of a crime
 - Continuously monitor and improve performance.
- Endorse the strategies from the 2013 National Symposium on Violence against Women and Girls with Disabilities as a matter of urgency, to develop capacity building or peer support programs for women living with disability in institutions, and ratify Commonwealth/State/Territory legislation to recognise all forms of violence against women and girls perpetrated in all settings, including institutional and congregate care settings.
- Consider implementing a national mandatory system for reporting abuse of people living with certain types of disability, as one element in a comprehensive range of measures.

JFA Purple Orange would be pleased to further discuss any aspect of this submission with the Senate Standing Committee on Community Affairs.