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SPEAKING UP FOR YOU INC protects and defends vulnerable people with disability through individual advocacy to address injustices and to make a positive and sustainable difference to their lives

Department of Social Services
Quality and Safeguards consultation
Via www.engage.dss.gov.au

Speaking Up For You Inc (SUFY) is an independent individual social advocacy organisation for adults with a disability who live in the Brisbane and Moreton Bay Regional Council region.

SUFY protects and defends vulnerable people with disability through individual advocacy to address injustices and make a positive and sustainable difference to their lives. The advocacy issues focus on the person's fundamental needs such as human rights, safety, health, shelter, food and appropriate support to live in the community

SUFY is a community based, non-profit incorporated association funded by the Federal Government and Department of Communities, Queensland.

Our submission addresses the question of how does access to independent advocacy impact on- the safety and wellbeing of people with disability . and the quality of the services they receive.

Questions from the consultation paper:

- Are there additional ways of building natural safeguards that the NDIS should be considering?
- What can be done to support people with a limited number of family and friends?

People with disabilities often experience, or are at least vulnerable to, discrimination, neglect, exploitation or abuse. Their rights, whether human rights or legal rights are commonly ignored and denied. Access to ways of enforcing those rights, while readily available to many others in society, may be restricted or denied to people with disabilities. Resources necessary to ensure the honouring and equitable recognition of those rights are often not provided. Where there are no recognised rights available to assist in a struggle for justice, something more is needed. Even where rights exist something more than the mere existence of rights is needed if those rights are to be respected, honoured, and protected. That something more+ is advocacy.

Advocacy challenges us to take responsibility for each other, and in particular for those among us who are most vulnerable. The need for advocacy for people with disabilities arises for a number of reasons: the impact of impairment, the social situation experienced by people with disability, the effects of human service systems and the effect of current social values especially in times of economic and social stress.

People who have a disability experience some degree of limitation to their physical and/or functional capacity, which can become life-shaping, and even life defining, in its impact. Although people who have a disability grow and develop across the course of their lives, this limitation is real, life long, and often has a major impact on the person's capacity to meet their

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**SUFY IS AN INDEPENDENT INDIVIDUAL SOCIAL ADVOCACY ORGANISATION FOR PEOPLE WITH
DISABILITY IN BRISBANE and THE MORETON BAY REGION**

own needs. Depending upon the degree to which the person's disability limits their competency, they will require additional supports from other people across the course of their lives in order for their needs and interests to be addressed, and sometimes even to ensure that they will live.

For many people in vulnerable situations, the capacity to make and maintain the relationships necessary that will assist people to talk over issues, deal with unexpected and life changing circumstances, makes the person more vulnerable to loss of opportunity to live a good life. These relationships cannot be replaced with service provision. Vulnerable people need people who have minimal conflict of interest, who can monitor, evaluate, envision and empower the person with disability to be involved in the decision making and choices that will impact on their life situation. Some people do have family, friends and allies who are there for them, but for many people, there is no one who has a good knowledge of the human service system and how it works. Independent advocates can provide the information and the advocacy necessary to ensure the person is supported well, obtains the services they need and maintain a monitoring role to assist when needs change.

For people with disability in Queensland their experience has often been no choice in regards to what service they use, where they live, who they live with, and how they spend their time during the day/night. The manner in which services have been delivered can result in breach of human rights.

Access to ways of enforcing those rights, while readily available to many others in society, may be restricted or denied to people with disabilities. Resources necessary to ensure the honouring and equitable recognition of those rights are often not provided. Where there are no recognised rights available to assist in a struggle for justice, independent advocacy is needed.

Advocacy assists the person to question the service provider, informs on policy and procedures that the service provider should be following and monitoring the day to day competence of the service by bringing up issues of neglect and abuse with the appropriate authorities.

Independent individual advocacy can provide important safeguards through knowing the right questions to ask, providing a list of questions to use when interviewing potential service providers. An important role of an individual advocate is to develop the questions, and support people with disability to interview service providers and see that the provider is held accountable.

Individual advocacy can assist with reducing the risk to vulnerable people, The Quality and Safeguards framework in the consultation paper has three components along a continuum. The first one is the developmental domain, and this is about recognising and enhancing people's capacity to safeguard themselves, so it is things like people knowing their rights, having information to make good decisions, minimising risk by having supportive relationships that are not connected to the service provider and having connections with an advocate who can be there as protector, defender, monitor and evaluator of the outcomes achieved under the NDIA plans.

Where people have no one in their lives except paid workers the potential to suffer abuse and neglect is significantly increased and those people should be able to access independent advocacy to make sure they have adequate support to be represented in making a complaint, to the service, to the police and the NDIA.

Independent individual advocacy can ensure that service provider practices do not exclude people with disability from their families or wider community. Advocates can assist individuals to understand their rights by providing relevant information, using face to face conversations, written information and assisting people with disability to attend workshops and conferences, making sure they have relevant information about contacts they might find helpful and providing information about the United Nations Convention on the Rights of People with Disability (CRPD) that can assist the individual to achieve a good life.

Advocacy outcomes

Example of SUFY's advocacy: Rose is a person with cognitive disability and Rose's mother contacted SUFY and asked for assistance to deal with serious concerns she had about her daughter's wellbeing. Rose had a broken collar bone, multiple bruises and was very unhappy when she was eventually allowed to see her mother. Rose was moved from the service and placed in respite while the issues of concern, physical abuse, financial abuse and illegal use of chemical restraint were investigated.

The Police were asked to investigate the injuries that Rose received while under the care of the service provider. The police interviewed all staff, however no one could account for Rose's serious injuries despite the fact that she has 24 hour care. All the workers reported that they did not know what happened to Rose. As Rose has very limited verbal communication she was not able to tell the police what had happened. The police found that they were not able to press criminal charges because they could not obtain sufficient evidence.

SUFY made a complaint to Communities and Disability Complaints Unit and we have been advised that the complaint regarding Rose's injuries has been referred to the Department's Compliance Unit for investigation due to the potential criminal nature of the matter.

SUFY also made a complaint to Communities and Disability Complaint Unit about the breaches to Rose's privacy where a video had been taken by a service staff member and the illegal use of chemical restraint. Both of these complaints were substantiated and the service has undertaken to develop and implement strategies to ensure that the service complies with the relevant Acts.

SUFY requested that the Public Trustee undertake a full financial audit of Rose's finances and as a result the service has been ordered to pay several thousand dollars back into Rose's account.

SUFY will continue to advocate for Rose to ensure she remains safe and is able to access appropriate support in the community.

Even though the following Safeguards against Abuse and Neglect exist in Queensland, they provide minimal protection for vulnerable people. Without strong independent relationships with family, friends and allies the person with disability is at risk of abuse and neglect.

- ❖ Disability Services Act 2006
- ❖ Guardianship and Administration act 2000
- ❖ Anti-Discrimination Act 1991
- ❖ Australian Human Rights Commission Act 1986 (Commonwealth)
- ❖ Disability Discrimination Act 1992 (Commonwealth)
- ❖ International Covenant on Civil and Political Rights (UN)
- ❖ Convention on the Rights of Persons with Disabilities (UN)
- ❖ Queensland Disability Service Standards
- ❖ National Disability Advocacy Standards (Department of Social Services)
- ❖ Public Trustee Act 1978 (Qld)

- ❖ Work Health and Safety Act 2011 (Qld)
- ❖ Work Health and Safety Regulation 2011(Qld)
- ❖ Public Service Act 2008
- ❖ Code of Conduct for the Queensland Public Service
- ❖ Queensland Criminal Code
- ❖ Housing Act 2003

The above listed legislation and conventions contain provisions drafted with the intention of safeguarding vulnerable persons with a disability from abuse and neglect in different circumstances. Some go further and seek to promote the human rights of persons with a disability one of which is the right to live a good life in the community. Whilst legislative intention is commendable, it appears that some of the above mentioned laws do not have teeth and do not protect a person with a disability or facilitate good lives for them in the community. Grass roots advocacy, of the type that SUFY provides, has the ability to observe and challenge human rights abuse and neglect when government actors and service provider are unable or unwilling to do so.

Often natural safeguards are not applied to people with disability. For example, if a child presents to the doctor with unexplained bruising, the doctor reports the incident to Child Safety. Our experience has been that for an adult with intellectual disability presenting with facial bruising, no investigation by the doctor to determine how the bruising occurred. The usual system failed the person with disability because the doctor did not investigate the incident. In many situations, if the incident does get referred to the police, the police do not investigate due to lack of reliable witnesses or evidence.

Ensure everyone has the basic things that people in the community take for granted: e.g. people with disability do not have the same tenancy rights that are afforded to other citizens.

Safeguards can include:

- Providing proper tenancy agreements which need to have the same standards as generic tenancy agreements,
- Having an independent advocate or access to a body like Rental Tenancy Authority (RTA)
- Having conditions and agreements that are compliant with relevant laws, we have special legislation that sets people apart and does not give the same protection as other citizens e.g. tenancy agreement is used to state people legal rights in relation to the tenancy, whatever accommodation situation the person is in, they should get an RTA form, not one from the service provider. The tenancy agreement should not be related to the person's support.
- Service providers are building premises and linking those premises to service provision. Where the service provider is also the landlord, the person with disability can become homeless if they move to another service. People need to be able to change service providers without penalty or loss of a home,
- The more segregated and isolated a person, the more vulnerable, especially in segregated settings where individuals are unable to call for help, having normal community safeguards in place, more than one service provider and being known in the local community,
- Recognise that people with intellectual disability are very vulnerable, Mandatory checks are not a significant safeguard. For people with intellectual disability are often vulnerable, not believed when abuse occurs, and that abuse can come from anyone, the cleaner, the gardener or the direct provider or a co-tenant.

- From SUFY's experience, many people have been abused by co tenants who have been placed together without adequate support, no checks or information about the person's history in relation to violence and abuse. This is very relevant in the private hostel system where there is no information about the person who might be sharing the bed next to you.

Complaints

People with disability are very dependent on the service when they need to make the complaint. They do not want to cause any upsets, and know that there is always retribution in some form. Often when a complaint is made there is no outcome and the situation remains the same or becomes worse. People are often not believed or have no credibility. People with disability can often find it hard to articulate what has happened and need support to form a complaint and to follow through. People can be worried about being exited from the service, have difficulty in finding appropriate legal advice and people with disability do not always receive a positive response from the Criminal Justice system when they do report an incident.

The current complaints system in Queensland has inherent weaknesses. It is internal to Disability Services which funds the services and is not independent. The actual process can cause more harm to the person with disability if they are not supported by an advocate. Vulnerable and isolated people with disability need an avenue to make complaints freely without retribution with support from an independent individual advocate, who has minimal conflict of interest and who can monitor the situation to ensure the ongoing safety of the individual.

Regarding additional safeguard using Barred Person List

- SUFY suggests a system where complaints are able to be accessed by potential users of the service rather than having a barred person list. This looks at the culture and values of a service, and ensures that abuses are known. The prospective user can check out the service's record on complaints and how they dealt with complaints. Current experience is that it is unlikely that a service provider will reveal any complaints.

Independent complaints systems

The advantage of an independent complaints system is that complaints are made public, the nature of complaints findings and recommendations and the outcomes are publicised.

Mandatory reporting must be in place, for people with cognitive disability who have suspicious or unexplained injuries and this to be monitored by a new Independent Disability Commission.

Community Visitors Scheme

If there is a community visitors scheme, the community visitors need to assess the situation under the CRPD, rather than using their own set of values to monitor and evaluate what is happening in a person's life. The Community Visitor should be guided by the principles and articles of CRPD and where individuals have no verbal communication, they should make sure other safeguards are in place so the Community Visitor is not relying on the service provider to report and explain. Vulnerable and isolated people need an independent individual who can monitor and evaluate the living circumstances of the person with disability involved. Where no informal relationships exist, an independent individual advocate is needed.

Where Individual Advocacy Made a Difference

SUFY advocated for a man that was tied to a kitchen table by his service provider for hours each day for a number of years. Restrictive practices were not in place or applicable. The Disability Services Act 2006 - s19 states that people with a disability have the same human rights as others and (c) live lives free from abuse, neglect or exploitation.

DCCS officers were aware and did nothing. Managers of the support service did nothing. The Community Visitor was requested to view this person in his home and even though s 223 of *the Guardianship Act* states that the purpose of the Community Visitor is *providing Community Visitors for visitable sites is to safeguard the interests of consumers at the visitable sites*. The Community Visitor found nothing amiss. When finally the police were asked to investigate whether a crime was taking place they concluded that *s 355 of The Criminal Code Deprivation of liberty of a person who unlawfully confines or detains another in any place against the other person's will, or otherwise unlawfully deprives another of the other person's personal liberty, is guilty of a misdemeanour, and is liable to imprisonment for 3 years* did not apply to tying a disabled person to a table. No one was charged. Only the continued work by an advocate was able to resolve this situation. What is often seen as abuse or a crime for an able bodied person was not seen by Government authorities as a crime when it is done to a person with a disability.

Self-Managing Participants

Underlying assumption is that people who self-manage are able to make decisions about what support they need, who enters their home, and how support is organised or performed. This is not government business. This is clearly articulated in the productivity commission *having dignity of risk*. NDIA needs to embrace the individuality of self-managing participants and at the same time provide provision for individuals who may wish to engage the support of an individual advocate to assist with negotiations and issues of concern.

Restrictive Practices

All service systems should recognise that restrictive practices are illegal and where they are used that every safeguard be enforced and every person on restrictive practices should have an independent individual advocate to monitor, evaluate, protect the individual; the person should have the same opportunity of choice and control under the NDIS as everyone else.

SUFY believes that there should be no special system for people with disability. People with disability need a society and a criminal justice system that responds appropriately to people with disability without prejudice or favour.

The actual name *Restrictive Practices* is a misnomer, this practice could be called *Constructive Supports* rather than Restrictive Practices thereby removing the negative connotations and placing the focus on support for the individual. In the current system, there is an inbuilt punitive result; there is no way for people to be able to express themselves in the same way people can generally, e.g. aggressive challenging act. E.g. I hate going to church now becomes *hates people*. All actions are examined, magnified and reported where normally, the behaviour might well be an appropriate expression of anger, frustration, pleasure or otherwise. People with disability are viewed differently from others in the community, responses to the behaviours are taken more seriously, and every little action is monitored and there is not discrimination between a serious action and a very minimal action. E.g. a person on restrictive practices now has staff noting when he giggles. This is supposed to indicate that he is becoming aggressive and will need containment.

An over emphasis on duty of care often leads to continued use of Restrictive Practices. How does the service actually assist the individual to move towards a more acceptable behaviour? People are often incarcerated and offered no support to live anywhere else. When restrictive practices are applied in facilities e.g. like a jail, bolted down beds and stainless steel facilities the question is not asked 'how could you support people in the community safely?' Consequently, people are in locked facilities.

Service workers for people with disability on restrictive practices are influenced by personal values, beliefs, fear or ignorance and this can lead to inappropriate restrictive practices being implemented. For example, misunderstanding or exaggerating notice of triggers 'wore twice, threw a towel' can lead to withdrawal of community access; there may be no discernment about a person's expression of anger or frustration; and this can then be regarded as behaviour requiring restrictive practices.

SUFY believes that early intervention and culture change within service provision and education of the police so they know how to respond to the situations can be instrumental in dealing with behaviours of concern.

When the service provider goes to QCAT to request that restrictive practices be implemented, the person with disability is often not at the table. This is due to a number of reasons. The individual advocate is often the only person who can argue against the restrictive practices and lobby for other solutions. An example is where an individual does not have adequate funding to live alone and therefore is placed in a group situation that activates and escalates the person's behaviours of concern. Often, the only way the service provider can manage the situation within the available funding is to 'contain' or to 'seclude'. The least restrictive option would be to let the person live on his/her own with appropriate funding.

The advocate's role would be to ensure that that positive behaviour support plans are followed and incidents are appropriately recorded; reviews are undertaken and that staff have proper training to manage the situations that may arise.

The advocate has an educative role to ensure that the CRPD articles and conventions are followed. Independent individual advocates can advocate that people not be placed in unsafe situations. e.g. people living in hostels, who may be sharing their bedroom with known felons; advocate against people being required to live in shared support accommodation where there are behaviours of concern and restrictive practices in place; ensuring that families can have access to visiting sons and daughters when they are living in group homes, hostels or locked facilities, ensuring that individuals have access to the legal system where necessary, and ensuring that services have developed individual plans that include risk management strategies in relation to health care and emergency situations in consultation with the person and family and advocate.

Independent individual advocacy can challenge restrictive practices.

Strong independent advocacy action can:

- Monitor and visit to person to see what is happening
- Represent the person's interests at QCAT
- Review positive behaviour support plans
- Gain legal representation for people in QCAT hearing
- Report to police about illegal restrictive practices
- Educate families about rights in relation to restrictive practices

Thank you for the opportunity to be participate in the consultation process, we welcome an opportunity to discuss the need for independent individual advocacy with you further.