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

REVIEW OF THE NATIONAL DISABILITY ADVOCACY PROGRAM

Introduction:

SUFY is an individual advocacy organisation governed by people with a disability and family members. SUFY's advocacy is grounded in a Human Rights framework that recognises the United Nations Human Rights Conventions as fundamental tools for advancing the rights of people with a disability in the Brisbane and Moreton Region.

SUFY is a well-established independent advocacy organisation that is funded by the Commonwealth and State Governments. SUFY is recognised as a robust, independent and professional organisation by people with a disability and other stakeholders in Queensland and has been instrumental in key milestones in the sector.

SUFY fully supports all models of independent advocacy: individual advocacy, self-advocacy, family advocacy, citizen advocacy and legal advocacy as each model is designed to empower people with a disability. Vulnerable people with disability must have access to strong independent advocacy so that their human rights are met.

The National Disability Advocacy framework is underpinned by the Human Rights Framework and ensures that advocacy will be conducted in a Human Rights Framework rather than by ideology or self-interest.

SUFY provides advocacy to people with a range of impairments that includes people with intellectual, cognitive, neurological, sensory, physical and psychiatric disability. SUFY's advocacy focuses on the vulnerabilities of individuals rather than their particular label or diagnosis.

SUFY also recognises that people from CaLD or NESB face additional barriers when attempting to navigate the service systems.

SUFY works closely with AMPARO Advocacy which specifically provides advocacy to CaLD and NESB people in the Brisbane area and provides a mix of individual and systems advocacy.

SUFY has strong links with Queensland Advocacy Incorporated (QAI), a funded systems advocacy organisation, to ensure that patterns and trends of human rights violations emerging in individual advocacy influences the formation of systemic advocacy priorities.

1. Models of Advocacy

Questions

1.1 *How do people with disability, their families and carers benefit when agencies are funded to provide only one or two models of support?*

To provide effective advocacy, community advocacy organisations need to ensure that people with disability are key stakeholders in the governance of their organisations.

Some advocacy types can co-exist together when adequately resourced and funded. In Queensland some advocacy agencies may offer both individual and systemic advocacy.

SUFY believes that the key to effective integration of different types of advocacy is the level of resources available to agencies to support information transfer and collaborative relationships. People with disability have a right to access different types of advocacy. SUFY suggests that the appropriate mix of advocacy types can only be determined according to the advocacy needs of the people in their local area.

While SUFY's primary function is individual advocacy, it does recognise and support self-advocacy. However, when people with cognitive disability have difficulty presenting their case, particularly where there is an imbalance of power, SUFY will step in and advocate on behalf of the individual. *(For example, where an individual depends on their accommodation, support and care from one provider).*

SUFY assists people to self-advocate by enabling them to have a say at meetings, providing information about their rights, strategies and plans.

This is illustrated in this case study:

Jenna is sixty years old, with mild intellectual disability, has lived with her family in the same public housing all of her life. The house was rented in her father's name and all attempts to have Jenna listed on the tenancy agreement were unsuccessful. Other issues with the house included the accumulation of many years of hoarding household items, building materials, groceries, and many items gathered from kerbside clean-ups, by Jenna's father and brother. Both of Jenna's parents have died, her father most recently died very suddenly at home and Jenna was left with no tenancy agreement with Queensland Housing.

Qld Housing wanted the premises for larger families and demanded that Jenna leave and remove all items from the property.

SUFY advocated for Jenna using a mix of self-advocacy and individual advocacy to inform Jenna of her tenancy rights, helped Jenna inform Qld Housing of her intention to stay in the house. It has been the only home she has ever known for sixty years.

Jenna attended all meetings, SUFY encouraged her to speak up about her unique situation. Jenna was very vulnerable and at risk of being made homeless. She was at risk of being evicted because her name was not on the tenancy agreement, Qld Housing was trying to hold her responsible for the hoarding in the house. Jenna had no authority to clean up or remove anything from the house while her father was alive. SUFY helped Jenna explain that the issue of hoarding was not Jenna's responsibility and was not grounds for eviction.

Jenna was not confident nor competent to deal with this situation by herself. SUFY assisted her to obtain information on tenancy rights, and to write a letter to Qld Housing, that made it clear to Qld Housing that she was not responsible for the condition of the house since she was not listed as a tenant. Jenna was not able to physically clean and clear the house.

The outcome of SUFY's advocacy was to attend all meetings with Qld Housing with Jenna. SUFY assisted Jenna to examine new accessible housing that met her needs, and ensured that the new housing was in her local community with the familiar supports around her.

By developing a trusting relationship with Jenna, SUFY was able to negotiate more vigorously on Jenna's behalf as well as assist Jenna to speak up for herself in relation to her tenancy rights and her lack of control over the results of her family's hoarding.

SUFY also helped Jenna inform her siblings that she would no longer take responsibility for their financial responsibilities, and provided support when Jenna tried to comply with Qld Housing regulations regarding the number of people who could stay in the new premises.

SUFY wrote a letter on Jenna's behalf to family members informing them of the risk posed by other family members moving in and taking up residence in the new premises, and that no belongings that were not Jenna's were to be brought to the house.

In this example, individual advocacy and self-advocacy exist side by side and SUFY provides practical support for individuals who can and wish to speak for themselves.

Recommendation:

While we recognise the importance of all models of advocacy the limitations of self-advocacy for people with profound cognitive disabilities should be considered and ensure that individual advocacy is also available for this group of people.

1.2 What are the drawbacks?

In Queensland some organisations only receive funding for one disability advocate to cover distances larger than Federal electorates. Due to limited resources, organisations have had to make compromises by sharing facilities with service providers in the local area. Perceived and apparent conflict of interest exist when this happens and advocacy actions and responses are compromised.

Confusion reigns and lack of trust exists for the vulnerable person with disability who is expecting an independent person to be on their side and no one else's, especially when the advocacy is against the very agency that is hosting the advocacy group.

It is not physically possible for one advocate to provide multiple types of advocacy such as systems, legal and family advocacy. The needs for each of these responses, time wise alone set up antagonistic functions within the organisation so at least one or more of these responses will be limited.

Government proposals for generalist advocacy services using the 'hub and spokes' models or the 'one stop shop' models are top down approaches that do not recognise people with disability as key stakeholders in advocacy development.

People with disability in Queensland continue to wait for adequate advocacy responses to their needs. To provide advocacy across this state will require more than a centralised phone number and some ad hoc local responses. Queensland requires adequate advocacy resources which allow for effective local grass roots advocacy.

1.3 How do we value and support the various models of advocacy while ensuring equitable access to individualised, fit-for-purpose advocacy, regardless of location?

NDAP needs to recognise the diversity of the communities that make up Queensland. The location of advocacy organisations is crucial to effective and relevant advocacy responses.

Advocates require a deep knowledge of the lived experience of people with disability in their local community. Advocates need to understand the culture and the discrimination and disadvantage they experience. In order to foster this understanding, advocacy organisations must be imbedded in local communities enriched by local knowledge, networks and relationships along with expertise of the relevant advocacy types.

For example: Lack of local knowledge and culture has meant severe limitations for individuals with disability and their families in having their human rights met, in finding adequate resources, housing and services.

To have an effective individual advocacy response, we must have on the ground advocacy, advocates who know the local situation and who have the trust of both the individual and families and the respect of the various services in the local area.

When individuals have complex support needs, or have communication difficulties, the only way to build a working relationship is through face to face contact.

The NDAP needs to look at the reality that exists in Queensland. If the advocate is not part of the community particularly in rural and remote areas, they will not be aware of the local culture/discrimination/disadvantage experience for people with disability. This is prevalent in Aboriginal Torres Strait Island communities where advocacy efforts with sustainable positive outcomes can only be achieved when local knowledge and connections are established and maintained.

In large cities and towns, e.g. Brisbane, Gold Coast, Moreton Bay Region, Townsville, Toowoomba, Cairns, Mackay, there is no funded family advocacy and Queensland has one funded state-wide systems advocacy group. Some individual advocacy groups do some systems advocacy, sometimes at the expense of assisting individuals in immediate need.

There is no directly funded family advocacy in Queensland. Families are expected to know what is possible for their family member, and to do this alone. Strong, well-resourced family advocacy can enable families to share information, lobby more effectively with large service providers to provide better accommodation and education opportunities for their family members.

NDAP funding and appropriate resourcing for advocacy development would recognise and preserve local knowledge, expertise and networks developed by advocacy agencies over the years, and support new and existing advocacy agencies to develop their responsiveness to the advocacy needs of people in their local area.

In Queensland the Combined Advocacy Groups (Qld) was established in the 1990's to share knowledge and expertise. This group included all funded advocacy groups which subscribed to the Charter and for many years this group met face to face once a year, information was shared across the state, strong working relationships were established, providing shared resources, knowledge, expertise, strategies and collective action.

With the withdrawal of resources this group can no longer meet in the same way, and now uses teleconferencing and piggy backs meetings when other events occur. While this may appear to be efficient, it is not as effective in developing the professional development of existing and new advocates in the field.

Distance and costs involved in travel in Queensland poses a unique situation that requires a different response from more populous states in NSW and Victoria and South Australia. Although much information can be shared across the State with effective use of evolving technology such as video conferencing, skype, electronic messaging we must acknowledge the human factor in advocacy.

People with disability, particularly people with cognitive disability require face to face contact, bringing people together to share information about human rights and entitlements under the CRPD, developing one on one relationships that know the unique circumstances faced by individuals and their families, recognising that one solution does not fit all.

2. Improving access to advocacy supports

Questions

2.1 How do we improve access for:

- people with disability from Aboriginal and Torres Strait Islander communities and their families?
- people with disability from culturally and linguistically diverse communities and their families?
- people with disability in rural, regional and remote locations?
- people who are very socially isolated including those with communication difficulties and those in institutional care?

Under the Boardman report 2008 *Review of DSQ Funded Advocacy Services in Queensland*;

“almost without exception advocacy agencies suggested that the best way to improve access to advocacy is to provide more and better resources for advocacy”.

“Of the 14 agencies that were subjected to the review, ten agencies reported that they had turned away prospective clients due to lack of resources.”

Some people are unable to independently refer to advocacy services due to the complexity of their disability and their vulnerability.

Unless advocates have local knowledge of people's situations, effective protection and promotion of people's human rights cannot occur. *For example, where they live – hostel or institution? What kind regulations they are living under – restrictive practices, forensic orders? What type of services they are receiving – block funded? Individually funded? Time limited response funding?*

These environmental factors must be acknowledged and appreciated so that a proactive approach can be taken to identify and advocate for individuals in these circumstances out.

The advocate/advocacy agency needs to be accepted as a real part of the community not a fly in fly out response. They need to be on the ground in the community, to build strong trusting relationships to introduce understanding about how exercising Human Rights in that community will work.

For example: Foetal Alcohol syndrome is often prevalent in ATSI communities and goes undiagnosed and unaddressed. Children and young adults often end up in the criminal justice system because of lack of attention and understanding of the need for specific responses.

In Queensland some individuals are subjected to Restrictive Practices. In many cases these Restrictive Practices have been initiated because there are no or few resources available to adequately support individual's complex needs.

There are not enough resources to bring about change in the Restrictive Practices legislation. Consequently individuals are being placed in locked facilities for long periods of time. These people are isolated and unable to self-refer to an advocacy agency. They are fearful of retribution if they do bring up issues and are invisible to the broader community. They certainly will not be ringing up a central office to ask for advocacy.

For example: Jack has an intellectual disability and although Jack had never been diagnosed with a mental illness or a dual diagnosis he had resided in one part or another of a health run institution for more than 30 years. As a child, Jack would wander off and this often placed him in precarious situations.

Professionals of time recommended that Jack be placed in Wolston Park. Initially he was to stay there only on weekends, however his behaviour became more disruptive and unpredictable, and by the time he was sixteen he was admitted to a secure institutional setting at Wolston Park fulltime. He spent the next 31 years detained within one part of Wolston Park or another.

Jack viewed his detainment as punishment as he states he ‘does not have a mental illness and has done nothing wrong.’

Jack was placed under his first Forensic Order in 1996, after already being in a secure facility for 16 years. This was a result of some alleged offences which occurred after he absconded from a day outing from Wolston Park. The charges were referred to the Mental Health Court.

The charges were

- o Break and Enter a home with Intent (2 charges)*
- o Stealing*
- o Serious Assault of a Police Officer to Resisting Detention*

Jack was placed on a 2nd Forensic Order in 2002 following an alleged offence which occurred when Jack absconded from hospital. Once again this charge was referred to the Mental Health Court.

The charges were

- o Indictable Offence*
- o Break and Enter*

Prior to these 2 incidents Jack had never been charged and he has not been charged since.

It quickly became apparent to SUFY in 2009 that Jack was living in an inappropriate, unsafe and unacceptable environment. It also became clear that his needs were going unmet due to years of systemic failure within government departments.

Even though Jack has an intellectual disability and no mental illness, Disability Services wanted no involvement. As Jack resided at The Park they saw it was Mental Health’s responsibility to meet Jack’s needs, care and wellbeing.

Disability Services knew that The Park were unable to provide the individualised support that Jack required and that he did not need or benefit from the rehabilitation and recovery model that was implemented in this health run facility. Jack’s situation was not seen as a priority by Disability Services and he was left to waste his days away in the Medium Secure Unit.

Following the Hon W.J. Carter Report in 2006 Jack was recommended to be placed in an alternative model of support - The Forensic Disability Service governed by the Forensic Disability Act 2011 and run by Department of Communities – Disability Services - is a contained facility for

people with an intellectual or cognitive disability who are on a forensic order and who would otherwise be detained in prison or a psychiatric facility.

The reasons given were that Jack required to live in an environment that restricted his absconding and that Jack was too institutionalised and had no skills in relation to living in the community. So of course the best thing for Jack was to move him to another institution.

For 36 years Jack has lived in an environment where every one of his behaviours has been constantly monitored and assessed, documented and reported on, analysed by professionals and then used to inform future decisions about his living situation and essentially his freedom. It has been 13 years since Jack committed his last alleged offence.

It was not until 2009 that SUFY became aware of Jack living in this institutionalised setting. Despite Jack living in a situation surrounded by professionals, he continued to be isolated and disconnected from the rest of the society, no one recognised the injustice of the situation and the abuse of Jack's basic Human Rights. SUFY has become proactive in seeking out people in institutionalised settings.

Recommendation: NDAP needs to recognise the importance of advocacy organisations establishing and maintaining on the ground relationships with the individuals and families, and be imbedded in the local community with local knowledge of culture, services and systems operating in that particular area.

3. Improving the advocacy evidence base and coordination on systemic issues

Questions

3.1 *What mechanisms could be used to ensure information on systemic issues gets to the right people and organisations?*

3.2 *How can we help disability advocacy organisations work with a wide range of other organisations with similar aims, such as:*

- *disabled people's organisations (DPOs)*
- *the Australian Human Rights Commission*
- *Ombudsman organisations*
- *aged care advocacy organisations*
- *state disability advocacy organisations*
- *peak bodies?*

Mechanisms currently in use include proactive development of positive working relationships across the sector so that SUFY is invited to contribute by providing case studies and examples of SUFY's work.

The case studies cover Human Rights, discrimination, housing support, legal systems including the criminal justice system, restrictive practices, transport and education and the critical impact of these services and systems in the lives of people with disability.

Examples of where this information is shared to highlight the complex and systemic issues that affect individuals include:

- The Combined Advocacy Groups Queensland Qld
- Human Rights Commission
- Community Safeguards Coalition – members include service providers, advocacy agencies and concerned community members who are concerned about forced co-tenancies in Queensland

- Community Legal Centres
- Professional relationships with statutory authorities – Public Guardian, Public Advocate and Public Trustee and the Qld Civil Administrative Tribunal (QCAT)
- Media outlets
- Griffith University and Community Resource Unit forms – assisted individuals to tell their story and relate to the audience
- Australian Centre For Disability Law
- Community groups which invite SUFY to present stories and case studies that highlight Human Rights and abuse and neglect at their forums
- Senate Enquiries- submission as well as presentation to the Committee
- The promotion of the Human Rights Bill at Parliament House - supported individuals to tell their stories

The NDAP has been collecting data for many years. Data collected needs to be analysed against the Human Rights principles.

For example: *Collection of data needs to reflect /indicate the incidence of abuse and where it is more likely to happen and the collection of data needs to focus on human rights.*

This data can then be used to cease funding for models of support where this abuse occurs.

This would inform government that some models of service are high risk and ensure adequate funding for people with high and complex support needs (challenging behaviours) so they do not need to live with other vulnerable people with disability.

*Recommendation: the NDAP should commit to a systemic data collection strategy, however, what is **more important** than the **collection** of data is **how that data is interpreted and acted upon** so that people's human rights are met.*

4. The interface with the NDIS and addressing conflict of interest

Questions

4.1 *What steps or organisational structures should be put in place to ensure conflicts of interest do not arise, or are minimised?*

Failure to recognise and manage Conflict of interest whether real or perceived will severely compromise any advocacy being performed for vulnerable people.

Key risk management strategies include:

- Ensure the organisation has a well-defined advocacy definition
- Organisation has a clear framework of Human Rights principles
- To be independent and to appear independent, disability service providers are completely separate from Advocacy organisations and are not funded by NDAP Framework
- Ensure the organisation has a Conflict of Interest policy
- Provide mechanisms for declaring potential Conflict of interest
- Individual workers recognise and declare and minimise conflict of interest where it arises
- Develop safeguards including recognising personal bias, monitoring, supervision, training, system of reporting/recording
- Provide clear job descriptions
- Advocacy agencies should remain independent of service providers,

4.2 *How do we avoid gaps between supports provided by the NDIS and advocacy funded by the NDAP?*

4.3 What policies and strategies do we need to protect the rights of people with disability?

The NDIS will not provide all the answers and safeguards! People will continue to be vulnerable because there are many systems that are meant to protect them are not perfect. *For example; People will still need assistance with statutory bodies such as the Public Trustee, the Public Guardian, the Community Visitor, discrimination issues, accessing Health services, Housing services and the justice system.*

- We can avoid gaps by funding advocacy appropriately, and by instigating a public awareness campaign targeted at people with disability, their families and service providers on the role of advocacy in the lives of people with disabilities and the advocacy options available to them.
- Policies should reflect the principles and be evaluated against a CRPD framework.
- Workers who provide planning, assessment under the NDIS must to be separate from the advocacy role.
- Using a risk management approach that looks at the likelihood of complications, sets steps in place to monitor, supervise and discuss circumstances where potential and actual conflict of interest arise.

Recommendation: the NDAP must ensure that disability advocacy is independent of service provision and should not be funded to deliver disability services under the NDIS.

5. Understanding and improving access to justice

Questions

5.1 *What forms of legal review and representation do people with disability need most?*

5.2 *What barriers prevent people with disability from accessing justice?*

When people with a disability become involved in the criminal justice system they experience fear and prejudice. The barriers that prevent them from accessing justice include:

- Law enforcement officers not recognising that a person has a disability and police taking statements with making sure the person has an independent 3rd person in attendance.
- Police “fobbing –off” a person with a disability making a formal complaint because the police believe that the person has limited capacity to understand the legal process and therefore there is no points in pursuing charges.
- People with intellectual disability who have little understanding of right and wrong being accused of assaulting support workers with no recognition of the negative emotions brought on by very poor service responses from the worker.
- People with intellectual disability giving incrimination statements and false confessions because they are manipulated, misled or confused.
- People with disabilities who have difficulties in communication , with legal practitioners

We are also concerned about the potential impacts that participants in the NDIS will experience when managing contracts with service providers. People with disability will be entering into private contracts to purchase personal service. They may require support to be able to understand the jargon and responsibilities of contracts and negotiate favourable, achievable terms of contract.

Additionally, people with disability need to be able link their goals to resources required to achieve their plan, using the right language and frameworks as required by the legislation.

5.3 *What models of legal advocacy are most effective?*

Disability advocacy services play an important role in assisting people with a disability to navigate the criminal justice system, providing them with high quality information and making referrals to legal advice and representation, undertaking negotiations with the police and providing advice and assistance in obtaining medical evidence.

For example:

- Specialised Human Rights legal Services that provide legal services to people with impaired capacity who are subjected to Restrictive Practices and Involuntary Treatment orders.
- Justice Support programs that assist people with a disability to get legal advice or representation and assist people to comply with court orders etc.
- Public funded legal assistance (legal aid)
- Disability Rights legal services that would build the capacity of the legal profession to meet the legal needs of people with a disability by ensuring lawyers are sensitised to the needs ,requirements and strengths and weaknesses of people with a disability.

Amongst the models of legal advocacy, private practice, legal aid, community legal centres both specialist and generic, the community legal centres have a greater understanding of the issues that affect people with disability. They also have access to networks and partnerships/pro bono lawyers to deal complex issues.

Recommendation: In terms of improving access to justice, the findings of the 2014 Productivity Commission Inquiry Report in Access to Justice Arrangements, estimated that an additional \$200 million a year should be provided to assist legal services to maintain their existing services and to address the gaps that impact on people with disability in their attempt to access justice.