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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

Review of National Disability Advocacy Framework
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.

Do you believe the current Framework encompasses your vision of advocacy in the NDIS environment? If not what changes are required

Definition of Advocacy

Whilst the meaning of advocacy in the review paper gives a view on what is advocacy, disability advocacy requires a much more detailed and focused definition if the work of advocacy is to address the actual need for advocacy. The definition provided in this paper does not recognise the essential advocacy undertaken for people lacking capacity to understand and exercise their rights. It is also essential to recognise that advocacy is not just about rights but also about needs, interests and well being.

We believe that funded disability advocacy needs to conform to the following definition to ensure people with disability and their families are supported and safeguarded.

Definition of strong independent advocacy for people with disability

Advocacy is speaking, acting and writing with minimal conflict of interest on behalf of the sincerely perceived interests of a disadvantaged person or group to promote, protect and defend their welfare and justice by:

- *being on their side and no-one else's;*
- *being primarily concerned with their fundamental needs;*
- *remaining loyal and accountable to them in a way which is emphatic and vigorous and which is, or is likely to be, costly to the advocate or advocacy group.*

Strong independent advocacy is needed because people with disabilities and their families 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

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 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.

Some examples include:

- (a) a person with a psychological disorder who experiences episodes of severe depression may, during such an episode, lack the volition necessary to meet even their needs for food, shelter and safety.
- (b) a person with cerebral palsy may be unable to communicate their needs and wishes without significant assistance, and others may not be able to understand, or be willing to respond to, the needs of the person.
- (c) a person with an intellectual disability may be unable to see and understand an injustice to which they are subject.
- (d) a person with a physical disability may be unable to move or gain access without significant adaptation of the physical environment.

In this context, the concepts of empowerment that derive from other social movements are not the whole answer. This difference must be clearly understood and taken into account in the planning of any advocacy efforts for people with a disability, in case the outcome of the effort may expose people to more neglect, exploitation or abuse.

The social situation facing people with disabilities

Because the person's difference is often perceived negatively by many people within our society, people with a disability are often socially devalued and degraded by the following means :

- (a) Rejection, sometimes by families, neighbours, community in general, and sometimes even by the service workers whose very income derives from the person.
- (b) Isolation and segregation from people who do not have a disability and therefore from opportunities that come from being in contact with other people.
- (c) Lack of opportunities for a person's development, growth and enriching life experiences, resulting in wasted lives.

- (d) Congregation with other people with disability and/or other devalued people, in circumstances where people may have nothing more in common than their shared rejection by other people.
- (e) As a result of segregation and congregation, people with disability are often not expected or encouraged to develop positive social roles such as partner, friend, fun lover, life enjoyer, learner etc.
- (f) Loss of control and autonomy whereby every aspect of life may be externally controlled by other people and/or the service system upon which they rely.
- (g) Material poverty which exposes people to such things as poor or no health care, inferior housing, and or homelessness thereby leading to illness, and shortened life expectancy
- (h) Loss of recognition of, and few opportunities to develop, a sense of individuality and uniqueness.
- (j) Physical and/or emotional neglect, damage or abuse from other people and the surrounding environment.
These life experiences may, at times, be so severe and intensive that the person's whole identity may be characterised by depression, pessimism, fear, personal insecurity or rage.

Effects of human service systems

The effect of current social values especially in times of economic and social stress Many people with a disability have a heavy reliance on formal, direct human services to meet many of their basic needs. Depending on their quality, these human services they can assist people with disabilities to live more valued and inclusive lives. Nevertheless there are a number of issues relating to human service systems and the need for advocacy that have been identified.

These are as follows:

- (a) Human services are imperfect and can never be made to be perfect. Therefore things will go wrong and there needs to be a number of strong safeguards in place to protect the interests of people. The more vulnerable the group of people, the stronger and more numerous the safeguards need to be.
- (b) Human services serve interests other than those of the individuals in whose name they have been established Interests include the person's family, the person's advocate, the service workers, union of professional associations, funding bodies, the neighbourhood, regulating bodies, and society. In these competing interests, the individual person is the least influential and their interests are often sacrificed to the interests of the others.
- (c) Human services often reinforce, rather than challenge, negative stereotypes of people with disability. By the way the organisation operates and the policies it adopts subtle messages can be given. For example, if a recreation service thinks it is not a good idea for a person with a disability to attend a generic TAFE class because he/she might disrupt others then they are giving a message that people with disabilities are not able to learn or develop and cannot interact with others.
- (d) Human services are likely to decline over time, due to:
 - inability to adapt
 - changing staff
 - loss of vision
 - difficulty in embracing critical evaluations of own service
 The day-to-day struggle to provide services may also lead to a hardness of attitude towards those people with disability they were originally set up to serve.
- (e) The service system lacks coherence and comprehensiveness. There are many gaps between services and a significant likelihood of non-responsiveness or poor co-ordination between services.

In addition many people cannot access services as the demand for services exceeds the services available.

Nor is there a fair means for deciding the basis on which people receive services.

- (f) Formal human services cannot meet all human needs.
Fundamental human needs for relationships, affection, security cannot be met by formal service structures but only by others acting freely and independently. The size and complexity of the human service system on the one hand and the vulnerability and powerlessness of people with a disability on the other means that the general principles of consumer, user and human rights protection are not sufficient and must be reinforced by other safeguards.

The effect of current social values especially in times of economic and social stress

Current social values include that a person's worth is measured according to health, wealth, productivity, intelligence, individualism, independence and attractiveness. These values are leading to a greater non-acceptance of, and indifference to, marginalised populations. As a result, social and economic stress is posing a greater danger nowadays to vulnerable and powerless people. On this basis, advocacy for vulnerable people may be more rather than less, needed in the future.

Are the principles of the Framework appropriate for guiding the delivery of advocacy for people with disability in a changing Disability environment, including in the context of the NDIS? If not what changes are required?

The principles for the Framework can be strengthened by including the articles from the Convention on the Rights of People with Disability (CRPD) that apply.

A key principle of advocacy required in our changing environment with the NDIS is the principle of advocacy independence. Independent individual advocacy is needed where people with disability are trying to have their voice heard and have their allegations and complaints taken seriously. People need someone independent who can be on their side, speaking on their behalf and addressing the power imbalance faced by dealing with service provider organisations and government. People need an advocate they can trust to be on their side, and no one else's.

Are the outcomes of the framework still relevant or should different ones be included? If so, what should be included?

Current outcomes have an expectation that people receiving advocacy will then be in a position to develop, inform and evaluate disability and broader government policies, programs and services that impact them. Many individuals with disability are not in a position to be directly involved in these matters and their needs, interests and perspectives may well be different for those who are interested. There needs to be acknowledgement that families, friends, allies and advocates are also able to inform these policies.

Are the outputs of the framework still relevant or should different outputs be included?

Outputs need to recognise the complexities and skills needed to carry out strong vigorous advocacy that will impact on people's lives and ensure focus on individual needs. The following case study provides an example of complexity and skill needed to negotiate the myriad of obstacles presented by the health system where the medical model decrees that care needs to be 24/7 with minimal family and community engagement.

Re Advocacy Nathan

Nathan had a severe hypoxic brain injury resulting in the need for high level care. This care entails bathing, showering, toileting, dressing, undressing, grooming, eating, mobility, transportation, monitoring and therapy. Other than smiling when he is happy, he does not have means of communication. Nathan became an Australian citizen in 2005. At the time he was a world champion chess player. He is not able to return to Peru because he was accepted as a refugee from Peru when he acquired his Australian citizenship and his high needs are so great that no airline would be prepared to transport him.

Nathan has reverted to his understanding of the Peruvian language and smiles when his mother, Cherie or Daries communicate with him in Peruvian, but he seems to have no recognition of what is said to him in English. As a consequence of his injuries he seems to have reverted to his original language although this may be temporary. Nathan is currently 29 years of age and is one of five children of his mother. Nathan is in an institution and cared for by his mother and his brother Daries seven days a week up to nine hours a day principally with respect to cooking his Peruvian food feeding him, communicating with him and assisting the orderlies in attending to his bathing and personal care needs.

Daries and Cheryl come into Australia

Daries came to Australia on 25 April 2024 in order to assist his brother, Nathan. His mother arrived on 14 July 2014. Both of them have bridging visas at present and we both applied for a carer visa from the Department of Immigration and Border Protection.

Daries and his mother are living in a flat in Brisbane. They are currently supported from his savings in Peru,

Family and Cultural Needs

In Peru, there are very few nursing home or aged care institutions. The elderly and those with a disability are cared for as part of the family. That is part of the culture of our family. It was abhorrent to Daries and to his mother and other members of the family that Nathan might be placed in a nursing home or other high care institution when we are both available and willing to look after him and meet all of his needs for the rest of his life. In Peru we do not have a culture of using a nursing home and it is our earnest desire and wish to take Nathan and to care for him, nurse him and look after him.

The Future

Nathan's application for social housing assistance has been approved as being a very high need by the Queensland Government. It is addressed to Nathan as the application was made in his name.

Daries and his mother visit Nathan seven days a week for approximately nine hours a day and take him for day visits out of the facility; Nathan wants to remain connected to his culture and with his family in order to keep him informed of what is occurred in Peru and bring him Peruvian food. It also refers to his goal to live with his family in their community and not remain in a care facility or to move to a house with shared support; Nathan would like to live with Daries and his mum in Brisbane. Nathan is Peruvian born and he needs and wants to remain connected to his culture.

Studies show the undesirability of young people with ABI to be placed in aged care institutions. There is presently no other institution available for Nathan. His complex and high needs need to be supported by his family with the assistance of financial support from Disability Services. His mother has left Peru where she has grandchildren in order to support her physically disabled son. Daries and his mum is prepared to give the rest of her life to his needs, both as carer and supporter, for the rest of Nathan's life. Daries is appalled that Queensland Health are now trying to shift Nathan to nursing home.

SUFY has advocated for Nathan that

- He be provided with a correctly fitting wheelchair when the family advised SUFY that the institution had provided him with a wheelchair that too small and was injuring him – new wheelchair was provided*

- *That the family and not the institution staff determine what type of housing that Nathan live in – SUFY took the family to meet with another family whose family member live with them In public housing in the community – Daries decided that the institution option of a group home was not a suitable option for Nathan and they applied for public housing for them and Nathan so that they could live together and be his carer. Seeking to maintain Nathan’s Peruvian culture and language and food.*
- *Advocated that Daries and his mother remain as the legal guardian of Nathan when the institution staff recommended to the Civil and Administrative Tribunal that the Public Guardian be appointed as institution staff wanted Nathan be placed in a nursing home and believed that the Public Guardian would facilitate this. This would have meant that Daries and mother would have had to return to Peru leaving Nathan alone in a nursing home.*
- *SUFY arranged that the family have access to a pro bono Barrister to represent them at QCAT*
- *Daries remain guardian and N***d remains in the institution waiting for housing and support.*
- *Daries unhappy with the plan mapped out by The Institution for Nathan’s future. SUFY facilitated a plan suggested by QCAT that Nathan access future planning that involved all stakeholders including DS, Housing, and The Institution and the family. New plan developed for Nathan that included living with the family in the community with adequate support. This plan was accepted by Housing and Disability services.*
- *Daries felt that he could not continue to live in Australia with no income. Needed to access a visa for a carer. SUFY arranged meetings for Daries with Senators and Members of parliament to request that they write to the immigration Minister. Daries and his mother are in the final stages of accessing a visa for carers.*

In conclusion, quality monitoring of advocacy efforts under the NDAP need to be linked to the human rights framework in the CRPD.