



SUFY

*About Our
Advocacy*

*Speaking Up for You
and our work with
people with disability*

October 2005

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1. OUR VISION, VALUES AND BELIEFS

Our vision

People involved with Speaking Up for You believe in the creation of a just society where people with disability:

- Are valued for who they are
- Are treated with respect and dignity
- Have their fundamental needs met
- Are free from abuse, neglect, isolation and exploitation
- Have a home and a decent quality of life
- Are able to move around their home and their local community
- Have typical relationships in family and community
- Have supports to enable their involvement in ordinary life
- Are able to participate and contribute in everyday life and hold responsibilities and valued roles in their community
- Are able to achieve their rights as citizens.

Yet we know that these everyday expectations are often not achieved by people with disability.

Why people with disability need advocacy

When a person has a disability, life can become very complex. Not only does the person have to deal with the impact that the disability has on their ability to do ordinary things in life, but also they have to contend with the negative attitudes of others, as well as the consequences of dealing with large human service systems. These service systems and the political agendas that drive them, can easily lose their way. The consequences for the person with disability can be that they live very impoverished and wasted lives, where their basic needs are not met and they become open to harm or neglect. People with disability therefore can become very vulnerable, especially when they have no voice and no mechanisms to influence positive change in their lives.

Although we need lobbying to get better governments, better services and better communities who are more responsive to the needs of people with disability, we also need something much more to redress the situations of the people themselves. We therefore believe strong social advocacy is needed to take up issues on behalf of vulnerable people with disability, to represent their needs and interests and to get them a better deal in life.



About vulnerability

People are likely to become vulnerable due to their impairment, when they:

- have complex needs
- are not able to speak for themselves
- cannot defend themselves
- have limited will to do life sustaining things
- have ill health
- are reliant on others to meet their needs
- have limited capacity to make decisions
- have difficulty in recognising danger.

Their social situation can also add to their vulnerability, especially when they:

- live on the margins of our communities, or behind closed doors
- are isolated and lonely
- have no people in their lives who will speak or act on their behalf
- are labelled and stigmatised
- are given no dignity or respect
- play no valued roles in family or community life
- have little support
- are living in poverty
- have no home
- are exploited, abused or neglected
- have little power to change their situation.

We also believe that the political and human service systems that have been established to support people with disability can lose their way and serve their own interests. They can sometimes promote negative stereotypes and myths about people, can deny their need for appropriate assistance and can maintain highly atypical lifestyles where people are not supported well and are not safe.

Poor services can increase people's vulnerability by:

- providing little support and having poor practices
- driving out family and other unpaid people of importance
- offering limited options and few opportunities to live ordinary life
- not really caring about the people they are serving and caring more about the interests of the workers
- having impoverished and punitive relationships with people
- congregating or segregating people on the basis of their disability
- controlling aspects of daily life and everyday routines
- maintaining a culture of abuse or neglect
- investing in life wasting or death making routines.



Why we do advocacy

We believe that people with disability should live valued lives comparable to those on offer to other citizens. They deserve no less. The people involved with SUFY know that the responses to vulnerable people with disability can be highly inadequate and that strong social advocacy is needed on their behalf. Advocates come across many people with disability in the greater Brisbane area whose basic needs for care, shelter and support are not met, some of whom live in very poor, unsafe, harmful or punitive situations.

We therefore take on the role of representing these individual's interests in order to influence positive and sustainable change in their lives. In our advocacy work we attempt to persuade people involved in services, governments and community who are in roles where they can make a real difference. We aim to meet people's fundamental needs and to address and resolve the unjust and harmful experiences and practices that impact on these vulnerable people's lives.

What authority do we have?

We take our mandate from our belief in the following important declarations, laws and principles which promote the rights of all people, as well as setting out expectations for the lives of people with disability.

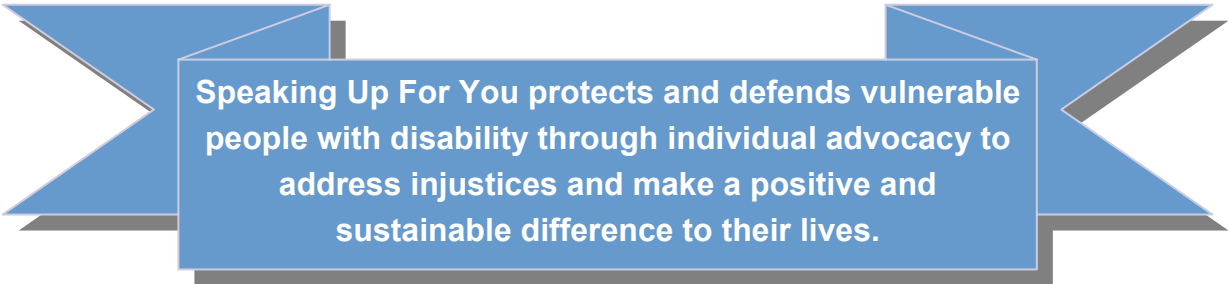
- Australia's being a signatory to the ***United Nations Universal Declaration of Human Rights, 1948*** and the ***United Nations Declaration on the Rights of Disabled Persons, 1975***
- The Principles and Objectives of the ***Commonwealth Disability Services Act, 1986*** and the ***Queensland Disability Services Act, 1992***
- The principle of **social justice** which incorporates:
 - Not only having the same basic human rights as other members of society, but also having the power to exercise those rights
 - Recognising the need to redress the balance of power, with fair distribution of economic resources and political power
 - Having fair and equal access to community life, and quality goods and services in areas essential to achieving and maintaining a decent lifestyle
 - Participating and contributing in personal decision making and in wider social, economic and political life
 - Having equal opportunity and the capacity to live without discrimination and achieve according to potential
- The belief that people belong together and can be **included** in the in the rich fabric and cultures of our diverse communities.



2. OUR MISSION AND OUR WORK

Our mission

SUFY’s mission is a promise of our organisational behaviour. This statement sets the direction for the work of our management committee and our staff and is continually referred to, so that all our decisions about our policies and practices remain in keeping with what we say we stand for.



Our advocacy filter

Our advocacy filter has 5 central elements which help with our clarity about what we do. They set the focus for the people we work with, who the advocates are, what we are working for and against, and how we go about our advocacy.

<p>For Whom? Identified individuals with disability who are very vulnerable, between the ages of 16 and 65, who are at grave risk and whose fundamental needs are not being met in the greater Brisbane area</p>	<p>By Whom? Paid individual advocates from SUFY who work on behalf of each vulnerable person with disability, or work on their behalf in support of their concerned family or significant others</p>
<p>For What? The person’s humanity, dignity, safety, freedom and survival Achieving their rights and justice Valued citizenship and inclusion in life Ethical personalised service responses Typical experiences and a good life</p>	<p>Against What? Abuse, neglect and exploitation, and other harmful practices Injustice, exclusion and segregation Poor and unethical service responses Homelessness and institutional practices Living wasted lives</p>

How Done
Individual advocacy
with some advocacy support, and small priority projects that inform our work with individuals

Each of these is expanded upon in the next section.



Advocacy for whom?

SUFY works with vulnerable people with disability between the ages of 16 and 65 who live in the greater Brisbane area in the shires of Brisbane, Pine Rivers and Redlands. The people we work with are those who are most likely to be at risk and are least able to represent or defend their own interests.

They usually come to our attention because their fundamental needs are not being met. By fundamental needs we mean the most basic aspects of ordinary life, for example adequate food and clothing, housing, health and well being, safety and freedom from harm, and having someone in life who cares.

Usually we hear about a vulnerable person with disability from a concerned worker or a family member, but sometimes we attempt to seek people out who may not always come to our attention in this way. For example when people are hidden behind closed doors we might keep a regular presence where we feel a person's well being might be suspect.

The situations in the greater Brisbane area where people with disability are very vulnerable are most likely when they are:

- at risk of eviction, homeless, or living on the street
- devalued or neglected, with their needs not known or not being addressed
- in institutional facilities such as mental health units, hospitals, nursing homes, hostels and boarding houses, group homes, or in prison
- in physical danger or in abusive situations
- at risk of making poor decisions which leave them open to danger and exploitation
- a threat to self or to others by behaviour that is seen as challenging
- without connections, poorly supported, in harmful or unstable living arrangements.

We attempt to have a presence in many of these areas and work with a diverse mix of people who differ in age, disability, complexity of support needs, living arrangements, culture, relationships and life situations.

The people we work with

Vulnerable people with disability

Aged 16—65 years

In the greater Brisbane area including the shires of Brisbane, Pine Rivers and Redlands

At risk with:

Fundamental needs not met (adequate food and clothing, housing, health and well being, safety and freedom from harm, having someone who cares)

Least able to represent or defend their own interests

Diverse mix of people who differ in age, disability, culture, living arrangements, relationships and complexity of life situations.



We believe that working with a diverse group of people strengthens our knowledge and understanding of injustice in the lives of people with disability. Through SUFY's work, we also help to create ripples of discontent in the many parts of the system that support people with disability poorly, often having beneficiary spin off effects for others who also are also struggling. Our gained knowledge of these systems allows us to liaise with and inform allied systems advocacy groups and local social action initiatives about the broader, systemic issues from our grass roots perspective of working at the level of real life.

We cannot work with everyone

Unfortunately we cannot work with everyone who is referred to us and would never be able to do so. We have quite limited capacity, as we are only a very small organisation servicing a heavily populated area with a large number of citizens with disability in dire situations.

Therefore we have to make some very tough decisions.

Although people who contact us require assistance to address many aspects of their lives, to attempt to do so would mean that those who are most vulnerable would never receive any advocacy. However we try not to leave people in the lurch, particularly when some suggestions can be made about where or how their issues can be dealt with appropriately.

We try to maximise our efforts and use our limited advocacy resources wisely by deciding that the people we choose to work with over the long term are in harmful situations and are without their fundamental needs being met.

We also try to add to the mix of people whom we already support. This is in an attempt to keep our work across a wide variety of situations. We therefore have to say no to many people who contact us, some of whom are very vulnerable.

We do provide some information and refer people to other agencies, and do some short term advocacy support as described further in the section on how we work. In those instances where the person does not fit the criteria for advocacy, or SUFY does not have the resources to carry out the advocacy, we inform the person that we cannot work with them and why, and offer relevant information or advice on strategies, give referrals to other agencies, and suggest others who may be able to assist them. Although this happens frequently by phone, we are not an information agency and this is not our core business.

How we decide

Does the person's situation fit our criteria and our priority for individual advocacy?

Has the person been involved with us in the past?

Is this a long term involvement or a short-term issue?

Do we have the resources and an advocate who has the capacity to work with this person?



Advocacy by whom?

SUFY employs three advocates, one of whom also coordinates the work of the office. SUFY also employs a part time administrative/resource worker plus some administrative support. All staff are guided by the principles and elements of social advocacy in their efforts on behalf of vulnerable people with disability.

The **advocates** are expected to form a long term relationship with each person because their situations can take considerable time to turn around. Through the relationship, knowledge and understanding of the person and their needs, they develop and hold a vision for the person's life and take strategic, ethical action in an attempt to influence others and to redress the person's situation. Advocates attempt to work on behalf of each person and in their best interest, to ensure that their fundamental needs are met. They aim to make a positive and sustainable difference to the person's life over time, without doing any further harm to the individual.

A small part of our work is in support of a family member or other concerned person in their advocacy effort on behalf of a vulnerable person with disability. However, most of the people with disability that SUFY works with are isolated, without helpful family members or other informal supports in their lives. Therefore, paid advocates may consider ways that others can be encouraged to be involved in the person's life in freely given relationships.

The **resource/administrative worker** handles many of the call ins and assists with information, referral and the resolution of short term issues, as well as doing the administrative work of the office and filling in for advocates during holiday breaks.

Advocacy for what?

The people involved with SUFY hold a vision for the life of each person with disability, and work towards ensuring the following:

- The person's humanity, safety, freedom and survival are guaranteed
- They are protected against further harm
- They have a sustainable home
- They have ethical, personalised services and supports
- They live a fulfilling life with a range of relationships, roles and opportunities, with participation and contribution in their community
- Their community is more aware and responsive to their needs
- They gain natural and restorative justice
- They achieve dignity, human rights and a decent life.



Advocacy against what?

SUFY works on behalf of vulnerable individuals to redress unsafe, unjust, harmful, isolating and devaluing situations where life can be wasted away. These situations are often found in living arrangements and other circumstances where negative stereotypes of people with disability are reinforced. Where people are hidden from public view without adequate supports, and few safeguards exist, then abuse, neglect, exploitation, coercion and degradation can easily happen, reinforced by a way of life of harmful practices. In other situations, the advocacy is against inaction on behalf of the individual, especially where neglectful or unethical people, services and systems have not taken on board what needs to happen to address the welfare, safety and fundamental needs of the person with disability, or where barriers prohibit ordinary life to be played out.

How we do our advocacy

SUFY's core business is Individual Advocacy on behalf of vulnerable people with disability.

Because the large number of people who phone in do have genuine concerns that we do not have the capacity to address, we provide some information and referral as well as some limited short term advocacy support. We have chosen to do a small amount of work in support of family members whose sons or daughters remain very vulnerable, despite their continued advocacy on the person's behalf.

We are also aware that the very nature of our work is often hidden from public view at the level of how real life is played out. Our advocates often bear witness to the atrocities that beset people with disability and therefore we are the conduits of information to other allies who work to influence systemic change that advances our individual advocacy efforts. These functions are complemented by our advocacy development work and the business of running an accountable advocacy organisation.

Our Functions

Providing individual advocacy (core business)

Supporting others in their advocacy on behalf of a person with disability

Informing allies in order to advance our individual advocacy efforts

Promoting the understanding and development of social advocacy

Running an accountable advocacy organisation



Our functions

1. **Our Individual Advocacy:** This work takes the majority of our time and effort with a small core group of people with diverse circumstances, who are all very vulnerable and do not have their fundamental needs met. Our advocacy work with them is long term, creating positive, real and sustainable differences to each person's well being and lifestyle over time. This work is informed by the principles and elements of advocacy, which are explained in the next section.
2. **Our advocacy support:** This much smaller part of our work happens in three ways. When a person with disability, family member or other concerned person cannot be supported by SUFY, they are given some information, contacts, or referral to another source. On occasions SUFY will become involved in a short term intervention that will solve a crisis, centred on the person's fundamental need (eg: in danger of losing housing). About 10% of our advocacy work is long term individual advocacy support with family members whose sons or daughters are very vulnerable, despite their own advocacy efforts.
3. **Informing and influencing allies:** A strong role of SUFY has been to encourage others to take up issues collectively on behalf of the people we advocate for. This part of our work develops and maintains our connection with our networks of allies in ways that will advance our individual advocacy efforts. Although we do not do systemic advocacy, our stories can inform others and keep them grounded in people's real lives. It is also a useful way for us to understand the current political climate and who and how to influence, when we are working on behalf of a particular person.
4. **Advocacy development work:** SUFY acknowledges the need to be part of the wider social advocacy movement in Queensland, so that our collective skills and expertise are well developed, improved and safeguarded over time. We therefore have a role in promoting the understanding and development of strong advocacy in Queensland. We also do this locally to identify and inform new leadership for our organisation for the future.
5. **Organisational accountability:** As SUFY is a funded incorporated body, we aim to run a coherent, sustainable and accountable advocacy organisation. In order to do good advocacy, SUFY needs a skilled and committed management committee to provide good governance and stewardship, so that the continuity and stability of the organisation are assured. We also need skilled and committed staff to run and manage an effective office and do the work of the organisation and of principles individual advocacy on behalf of vulnerable people with disability.



3. ABOUT OUR ADVOCACY EFFORTS

Our definition of advocacy

The word *advocacy* usually means the act of pleading publicly in favour or support of someone or something. However, as evidenced from history, advocacy on behalf of vulnerable people with disability can be used for good or for harmful purposes. Advocates can be discerning about what they promote and how they go about their work so that vulnerability is reduced and that the outcome for the person is having a better life. However an advocate can promote things that are harmful, or do so in ways that raise the person's vulnerability, resulting in situations that give rise to abuse or neglect or even to the death of a person (as happened in the era of eugenics and also during Hitler's regime).

Therefore **advocacy is dependent upon the values base of the organisation and people who take on advocacy roles**, as well as on the considered approach of doing no harm. SUFY adopts the following definition because it implies a values base that fits with our vision for people with disability and attempts to clarify how we work with good intent.

Individual advocacy is speaking out, acting or writing with a minimal conflict of interest on behalf of the sincerely perceived interests of a disadvantaged person 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 over time in a way which is emphatic and vigorous and which is, or could be, costly to the advocate or advocacy group.

The principles that guide our practice

1. Human Rights

SUFY will promote, protect and defend the lives and the human rights of each person with disability whom we support in an advocacy relationship.

2. Social Justice

SUFY will operate in ways that support the achievement of rights, equity, access, participation and equality in our advocacy work with each person.

3. Inclusion in Community Life

SUFY will operate in ways that value and support the inclusion of people with disability in the life of their diverse communities.



What the elements of advocacy mean to us

The definition of advocacy sets out some very important elements for our work:

- **Acting to influence:** Taking considered, ethical action on behalf of the person with disability by writing, speaking out or doing other influential things that will make a positive and sustainable difference to the person's life
- **Being on the side of the person:** Being clearly biased in their favour, being true to them and representing their sincerely perceived needs and interests to others in order to influence good outcomes for the person
- **Being independent:** Being outside the formal service systems which impact upon the person's life and acknowledging and minimising personal and other situations that can cause conflicts of interest
- **Understanding the position of the person:** Developing a relationship which allows deep knowledge of who they are, what their life is like, and their real and potential vulnerability
- **Focussing on the person's fundamental needs, welfare, and interests:** Working on what the person needs most and operating in the person's best interest in order to promote, protect and defend their well being
- **Holding a vision of a good life:** Working towards long term goals of a good life in ways that promote the person's humanness and positive image, ensure their safety and security, and defend their rights, well being and inclusion in community life
- **Having an ongoing presence:** Remaining in the person's life and working in ways that do no further harm, using compromise, but never selling out
- **Working vigorously:** Having strength of conviction and working with a sense of urgency, indicating the necessity of positive change, yet acting in good faith, using common sense, influence and reason, and being strategic
- **Remaining loyal and accountable:** Being faithful to the person over the long haul with recognition that turning people's lives around can take considerable time and effort and persisting even if the going gets tougher
- **Being aware of the costs:** Recognising potential and real damage to the person, the advocate and agency when in opposition to the status quo
- **Having clarity of purpose:** Remaining coherent with the expressed values of SUFY and the principles and elements of advocacy, and remaining focussed on our mission and core business of individual advocacy
- **Not becoming just another form of service provision:** Not being just another case coordinator, counsellor, complaints or lobby group.



Framework for our decisions around best interest

Our work often involves making considered decisions on behalf of the person we are advocating for, because the people we work with are most likely to be towards the right end of the spectrum on each of the following variables:

1. The person’s level of vulnerability



We consider what we know about the person’s situation and how well their fundamental needs are being met (adequate food, clothing, health and well being, housing, safety, freedom from harm, someone who cares)

2. Their capacity to make decisions



We consider what we know about the capacity of the person to express their own needs and wants and their capacity to make decisions which do not add to their vulnerability and do further harm

3. The approach



We consider what we know about the seriousness of their situation, the political and social context and the person’s ability to drive their own agendas forward with positive action and outcomes.

Making decisions on behalf of other people is very complex and fraught with many moral dilemmas. The process involves our making judgements about perceived need and the person’s best interest which is much like walking the line between neglect on one side and over control on the other.



We try to use commonsense in how we go about thinking this through and seek information about a range of things that are of influence in the person’s life.

- The person’s sense of what they can tell about their situation
- Information from significant others, such as family members or close friends
- Information from other people in their life, such as service workers
- What we know about the person’s living and social environment
- How these sit with SUFY’s values and what makes a good life.



Our Strategic Planning Goals

Speaking Up for You has five major goals which set the direction for our work:

1. To provide individual advocacy on behalf of vulnerable people with disability whose fundamental needs are not met
2. To assist people to advocate on behalf of a vulnerable person with disability
3. To inform and influence allies and others to bring about systemic change to advance our individual advocacy efforts
4. To promote the understanding and development of advocacy within SUFY and in the wider community
5. To operate a principled, effective, accountable and sustainable social advocacy organisation.

These goals are indicative of our functions, however we recognise that the great majority of our work will be around our core business goal of doing individual advocacy.

1. **To provide individual advocacy on behalf of vulnerable people with disability whose fundamental needs are not met**
 - 1.1 Identify vulnerable people with disability who SUFY will advocate for
 - 1.2 Build a relationship with the person and an understanding of the situation
 - 1.3 Take action to meet the person's most urgent needs
 - 1.4 Develop a plan which details an appropriate advocacy response
 - 1.5 Take action to promote, protect and defend the person's interests and well being
 - 1.6 Reflect upon the process and outcomes of the advocacy effort.
2. **To assist some people to advocate on behalf of a vulnerable person with disability**
 - 2.1 Provide limited information, referral and strategies for people in dire situations who SUFY does not have the capacity to support
 - 2.2 Identify a small number of concerned family or significant others who SUFY will assist in their advocacy effort on behalf of a vulnerable person



Our Strategic Planning Goals

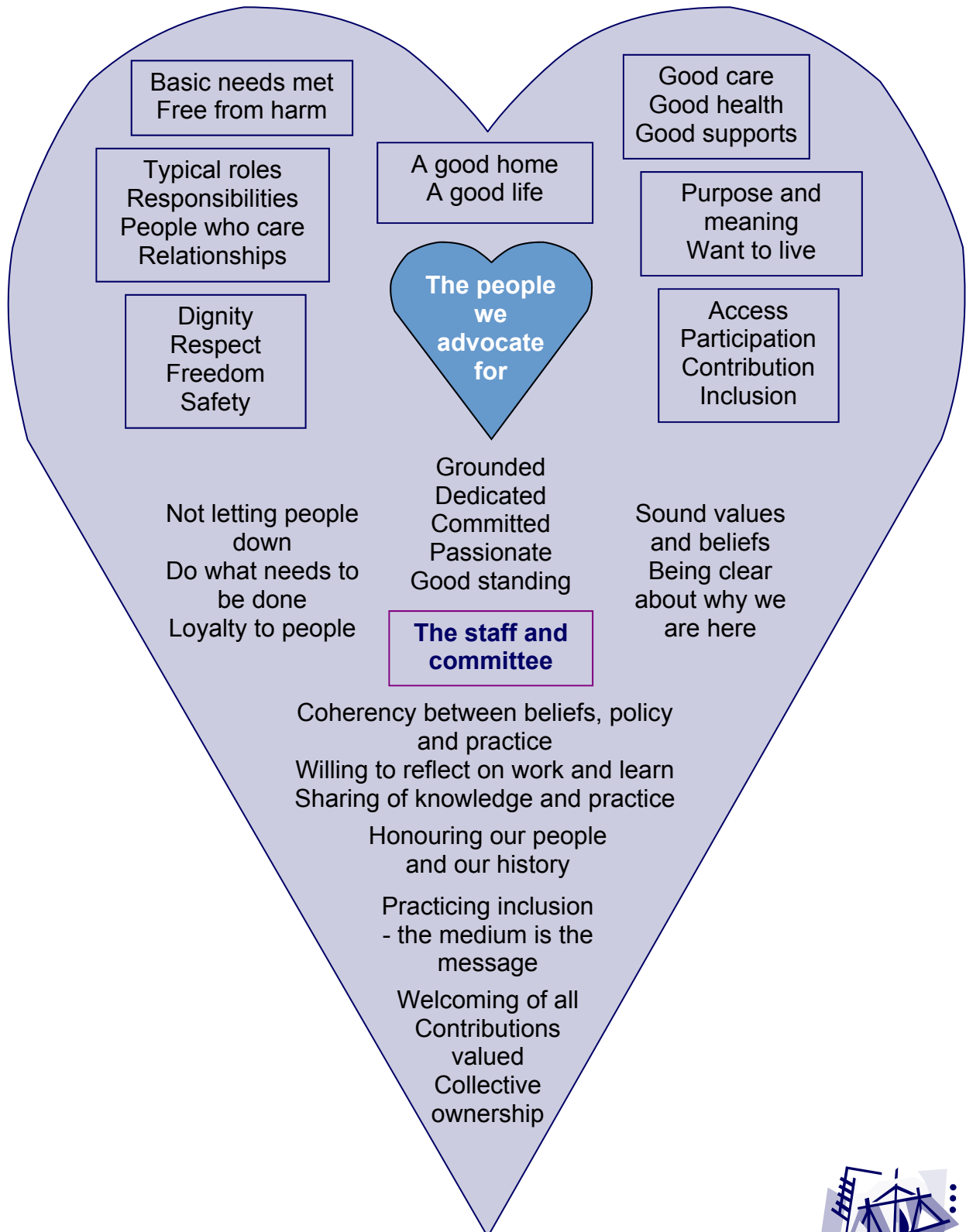
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- 2.3 Build a relationship and an understanding of the person's situation with the concerned person
- 2.4 Develop an advocacy plan on behalf of the person with disability in conjunction with the concerned person
- 2.5 Support their advocacy effort and reflect on its process and outcomes.
- 3. To inform and influence allies and others to bring about systemic change to advance our individual advocacy efforts**
 - 3.1 Identify priority areas where systemic change is needed to make our individual advocacy more effective
 - 3.2 Bring priority areas to the attention of groups and individuals who can work to bring about systemic change
 - 3.3 Manage the tensions created by this role on our work with individuals
- 4. To promote the understanding and development of advocacy within SUFY and in the wider community**
 - 4.1 Provide opportunities for people to learn about social advocacy and the work of SUFY
 - 4.2 Support the development of advocacy in Queensland
 - 4.3 Support the building of a strong social advocacy movement in Queensland
- 5. To operate a principled, effective, accountable and sustainable social advocacy organisation**
 - 5.1 Develop a dedicated, competent management committee to govern the organisation
 - 5.2 Develop a dedicated, competent staff to do the work of the organisation
 - 5.3 Foster good relationships between committee and staff, and with the wider membership and community
 - 5.4 Encourage continuous improvement of the organisation's work
 - 5.5 Maintain organisational strength and coherency over time
 - 5.6 To be an efficient and effective organisation, compliant with the requirements of being an incorporated, public funded body.



4. The Heart of SUFY

We believe these aspects lie at the heart of SUFY's work.



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This description was written by Jan Dyke following a workshop with management committee members and staff of SUFY
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