

# Self Advocacy Support Workers

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## Code of Conduct

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### 1. Introduction

The development of principles or codes of behavior to guide self advocacy advisors is crucial to the self advocacy movement.

The purpose of this paper is to discuss what makes a good self advocacy advisor or support worker, and the principles/ideals that should be upheld in order to achieve this ideal.

This paper is a starting point for self advocates, support staff and self advocacy partners to begin talking about how self advocates are best supported. In addition this paper prompts discussion which, ending in a code of conduct style document, will inform new staff of standards and expectations of the role of advisor and hopefully give new insights into the role for more experienced staff.

This discussion paper was developed with the assistance of a number of self advocates, advisors and academics. Each was interviewed and a set of open ended questions were discussed, these included:

- What makes a good support worker?
- What advice would you give to new support workers?
- When hiring a support worker what types of qualities would you look for?
- What makes a bad support worker?
- Can you think of times in the past when support workers did not meet your expectations?

Participants were also asked about personal philosophies underpinning their work and drew on personal experience when answering questions. In addition to this many publications from self advocacy chapters and resource groups in Australia and worldwide were also used to ascertain what self advocates wanted in a support worker.



## 2. Power and Control

Throughout the interviews and in the literature ideas of misplaced power and control in a self advocacy group were brought up. In the literature many self advocates sighted '*someone who does not take over*' as one of the primary requirements of a support worker; they strongly clarified that the role of a support worker is to assist rather than direct the group.

In the literature it was stated that the role of the support worker is complex and requires the individual to walk a fine line between supporting self determination and protecting the interests of the group. Much of the literature stated that the role of the support worker is easy to corrupt due to the amount of power and trust given to the support person (Fyffe, McCubbery, Frawley, Laurie & Bigby, 2004).

Many interviewed stated that in the past they had or had heard from colleagues that support staff would often take over groups, and push their own ideas before those of the self advocates. Many used words like '*bossy*', '*controlling*' and '*domineering*' were used to describe what they didn't want in a worker or had previously experienced in a bad worker.

Self Advocates interviewed said that a good support worker was someone who hands power back to the self advocate. These people always strive to disempower themselves and make sure that the control of the group is with the group.

*"(a good support means) Not to domineer people with an intellectual disability. To let them have their own say when they are well and ready and comfortable with it".*

~ Jane, Self Advocate

*"A good support worker listens and doesn't take over. These people understand that we are the experts on the support we need. You should always ask before you say something or do something "Do you mind if I..." Always ask. One of my good support workers would always ask "Heather, I have an idea do you mind if I say something?"*

~ Heather, Support worker and Self Advocate



## 2. Power and Control

These issues of power and control were no less prevalent in support workers major concerns. They also stressed the importance of empowering the self advocates first and foremost in their work. Many felt that all ideas needed to be directed by the self advocate being supported. It was stressed that in being a good support it was important that you take the time to discover what action the self advocate wants to take rather than the action you think they should take. One support worker expressed that it was important to always clarify that your role was to support and not direct.

Time and time again, a natural power imbalance existing between self advocate and support worker was referred too. Taking control of a self advocacy group was more than once described as the default setting for many workers, but it was up to them to always endeavour to hand that power back to the self advocates where it belonged.

“A good support worker supports choice making and supports actions. Self advocates should not come to the support worker when they have an idea, they should come to the group. The key role of the support worker is to make sure that is where the power lies.”

~ Paul, Associate Professor

“The support worker is basically there to support the group, not to try and take control. Some people might want to do things their way and say stuff to the group”.

~ Paul, Self Advocate

“I had always thought that the group belonged to the self advocates and I thought that they knew that too. One day I had this overwhelming feeling that maybe they didn't know and I asked them “Who do you think is the boss of the group?” Right away the members responded with ‘You are’. I had to explain to them that the group was theirs, it belonged to them. Now when I ask the group who is the boss they shout ‘We are!’ ”

~ Daniel, Support Worker



## 2. Power and Control



### Reflections on Power and Control

- What are your own experiences of power imbalances in your work as a support worker/ advisor?
- How do you make sure control is always with the self advocate?
- What actions do you put in place to ensure self advocates decisions are always authentically theirs?





### 3. Conflict of Interest

When interviewing support people one issue that came up a number of times was the notion of a *conflict of interest*. For the support person this could mean a number of things from conflict with a funding body to conflict with one's own values and beliefs.

The literature defined this conflict as *"when the groups needs go directly against the needs of the advisor"* (Worrell, 1988). All agreed that managing this conflict of interest and always having transparent relationships with the self advocate was vital to a successful working relationship.

In the film '**Support Workers Talk**' (n.d) one of the advisors stated that it was important that *"a support worker identifies their own internal conflicts"*. By internal conflicts they were stating that for a support worker to best do his or her job, they had to know what their own values were and have an understanding of their motivations before offering an opinion and support.

'A bad support worker is one who speaks for the person they support, it is not your job to have an opinion.'

~ Leanne, Support Worker

"A key role of the support worker is to avoid conflict of interests between the organization and funding. They need to ensure that the space for the self advocate's voice is not lost."

~ Paul, Associate Professor

"It is the support workers role to keep self advocates informed about any conflicts of interest. Self advocates often won't question the ideas of a person in power. Sometimes giving your own opinion even can change the way the self advocate thinks."

~ Support Workers Talk Video



### 3. Conflict of Interest

Another important conflict of interest that was brought up in the research was the conflict between funding bodies' needs, and the self advocacy group's needs.

The research stated that one of the key roles of a self advocacy advisor was to avoid this conflict of interest so that the self advocates could authentically represent their own opinions in every project that they undertook.

For the self advocates *conflict of interest* was a direct threat to them achieving the work they set out to achieve. If the ideas of the support worker conflicted with the ideas of the self advocate, they stated that most times the idea of the support workers ideas would go ahead. For self advocates, the withdrawal of support from an advisor often meant the end of a project and could be incredibly frustrating.

"A good support worker doesn't put in their view. Often I have seen a support worker talk the person with the disability around and manipulate them into thinking what they think."

~ Heather, Support Worker and Self Advocate

"If we (self advocates) don't agree with what their (the support workers) agenda is it is really, really hard to change their minds. If you want go a certain way and they don't agree it is really hard to do anything..."

~ Colin, Self Advocate





### 3. Conflict of Interest



#### Reflections on Conflict of Interest

- When have you experienced a conflict of interest between a funding body and the self advocacy group? How was this resolved?
- How do you work together with the advocacy group to make them aware of any conflicts of interest you may have, whether they are cultural, employment based or a differing of opinions?
- How can the code of conduct represent issues around conflict of interest?





### 4. Accountability and Professionalism

Something that came up in a few interviews with support workers was ideas of *accountability and professionalism* in an advisors day to day work. These were cited as particularly important due to the isolating nature of support work.

The idea of accountability in the work of a support worker and that it was the workers duty to foster an environment where being accountable for work was actively encouraged. Support workers felt that managing workloads, specifically effective time management were important attributes of a good support worker.

Throughout the research and during the interviews it became apparent that support workers felt strongly that it was each individuals workers responsibility to account for their actions and police themselves in that working environment.

"One of the key roles of an advisor is to constantly recognize when you make mistakes, to reflect and always review what you do."

~ Sue, Support Worker

"Accountability and transparency are important – this is especially effective when the advocacy advisor is accountable to the members of the advocacy group."

~ Daniel, Support Worker

"A support worker/advisor can't have a bad hair day, whatever your problem is you need to leave it at home. Your presence can make all the difference in the time you are with someone. You need to always have a degree of professionalism."

~ Emmy, Support Worker



### 4. Accountability and Professionalism

Some of the key ways a support worker needs be mindful of when acting in a professional manner according to the interviews and research are;

- That they take criticism gracefully ~ Colin, Self Advocate
- Admitting when they are wrong and learn from mistakes ~ Heather, Self advocate and support worker
- That they are reliable and can be trusted with confidential information (*Lawson, 2006*)
- Acting in a professional manner means being organized and being prepared for things like meetings ~ Heather, Self advocate and support worker and Associate professor, Paul
- Viewing and treating self advocates as valuable and competent equals (*Reusche, 1991*)
- Having good time management skills ~ Daniel, Support Worker
- Never acting in a patronising way ~ Lisa and Peta, Self Advocates
- Remaining neutral at all times in the problem solving and decision making process, acts as a referee to disputes inside the group (*Browning, 1997*)
- Using appropriate language that can be understood and that does not communicate attitudes and opinions that are offensive or prejudice ~ Tim, Self Advocate (*Self Advocate Coalition of Kansas, 2006*)
- Creating an atmosphere where they can step back, giving responsibilities to the group as they become more experienced with a vision to one day not being needed. (*People First of Missouri, 2002*).



### 4. Accountability and Professionalism



#### Reflections on Accountability and Professionalism

- How often are you appraised by the people support?
- Do you foster an environment where the people you support can feel comfortable in asking you what you are up to?
- Are issues around accountability something you feel is important for a code of conduct?
- What do you think constitutes professionalism in the role of an advisor?





### 5. Building a Relationship; Trust and Friendship

Throughout the interviews and in the research, building relationships came up as crucial to a successful working relationship between the self advocate and their support person. It was stated that *“Supporters need to get to know us as individuals, it should be a relationship based on honesty and trust” (Lawton, 2006)*. It suggests that friendly working relationships and socialising are a vital part of good support; self advocates will often find it difficult to work with a stranger. Further, the literature suggested that it was important for an advisor to develop a good rapport with each member of the group so that increased communications and trust could lead to the advisor gaining a greater understanding of the individual’s strengths and interests (Woodward, N.D).

The interviews mirrored what was found in the research, that building a rapport or friendship with the self advocate was vital for working relationships. The interviewees stated that due to the sometimes high turnover of support workers building a relationship can take a time. Without building these relationships self advocates said they find it hard to open up and ask for help. For support workers this can mean that they will often hesitate before seeking assistance.

Without appropriate relationship building the support worker will not know the skills of the individuals, hence have no understanding of their working capabilities or interest areas.

“Being a support worker is not like a friendship for you to unload on, it’s more like a one way supportive friendship.”

~ Emmy, Support Worker

When the person with intellectual disabilities gives that person (the support worker) a promise to keep and they can keep it to themselves that’s when the person will gradually trust them and build a friendship. They (the person with intellectual disabilities) will test you out, to see if you can be trusted- it might take 6 months or a year. You can help them better if they trust you.”

~ Jane, Self Advocate



### 5. Building a Relationship; Trust and Friendship

In the interviews respect was also mentioned numerous times as something that stood out in a support worker. This ensured a good relationship with the self advocate and was an essential part of the support worker role.

Some felt it was essential for the support person to set an example with the way they interacted with the self advocacy group so that others would see the right way to relate to the group respectfully and professionally.

“One of the important roles of the support worker is to treat the people you support the right way, You need to respect them and engage with them to set an example to the public on how to treat the individual or group.”

~ Heather, Support Worker





### 5. Building a Relationship; Trust and Friendship



#### Reflections on Building Relationships

- How do you build trust between yourself and the group you support?
- How important do you feel friendships are in the self advocate/support worker relationships?





### 6. Doing with instead of doing for

For support workers the blurred line between worker and advisor can become quite confusing. The literature describes a self advocacy advisor as someone who is a resource, a bank of knowledge and an organizer. The literature also states that *"in their eagerness to overcome problems for others people often forget that those others will have their own view of things and will want to make their own choices"* (Brooke, 2002) which infers that because of the time constraints and their own eagerness to help support staff can sometimes forget their role and simply do the task themselves. It goes on to suggest that if the advisor does more than is necessary the group will have *'difficulty making its own decisions, acting on those decisions and taking responsibility for those actions.'* (Woodward, N.D) The literature also suggested that when the advisor helps too much the growth and development of the group will be stifled (Simons, 1992).

When interviewed the support workers and self advocates held similar ideals. The self advocates stated that the best support staff were those who prompted and encouraged (without bossing) them to do it for themselves.

When interviewed both self advocates and support staff agreed that over supporting was disempowering to the self advocate, and that knowing when to step back and let the person work was a skill vital to good practice.

"One of our best support workers would put the ball back in my court. She would ask us what we think we should do. She wouldn't give us the answer but she would make us tease it out."

~ Colin, Self Advocate

"The advisor role can be tricky, because its purpose is to help members gain power over their own lives and their own movement. If the advisor does too little nothing may happen in the group. But if the advisor tries to lead and control what goes on within the group, the members may find it difficult to learn or exercise their capabilities."

~ 'The Self Advocacy Movement, Opportunities for Everyone' (n.d.)





### 6. Doing with instead of doing for



#### Reflections on Doing with not for

- Do my actions decrease dependency on me and encourage others to take on my role?
- How do I work each day to ensure that I enhance the self reliance of the group's members?
- Do you think this is something that could be addressed further in a code of conduct for support workers?





### 7. Being a great Support Worker; where to from here?

The role of self advocacy support worker can be a lonely and challenging one, while at the same time can be incredibly rewarding.

For self advocates a good support person means having a resource that can help support them in achieving the goals and dreams of the group. This is a person they can share ideas with, receive support from and use as a bridge that makes the changing world more accessible. For the support person the joy of their work lies in seeing others achieve their dreams and being part of a growing movement promoting human rights and equality.

The purpose of this discussion paper is to use the points raised to create better standards for self advocacy advisors.

"An Advisor should have the ability to lend a helping hand, provide a shoulder to cry on, lend a listening ear and bestow encouragement as needed. They will possess the ability to wear many hats, assume the numerous roles and leap tall buildings in a single bound."

~ The People First of Missouri, 2002

"Every Self Advocacy Group deserves an Advisor who is able to act as a resource person for the group members and who is capable of helping members settle disputes, plan activities, and set goals which do not reflect the opinion or goals of the advisor."

~ Self Advocacy Support Workers or Advisors Jobs, N.D



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This **Code of Conduct** is part of a **Support Workers** kit produced by  
the Self Advocacy Resource Centre

SARU acknowledges the support of the Victorian Government.

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