



Victorian Advocacy League for Individuals with Disability Inc

ABN: 949 763 281 00

235 Napier Street Fitzroy Vic 3065

Phone: (03) 9416 4003 Facsimile: (03) 9416 0850

E-mail: office@valid.org.au www.valid.org.au

Individual Advocacy Policy & Guidelines

(Includes revisions 9.1.2 & 9.1.3 to reflect the VALID Position on the Use of Facilitated Communication, August 2011)

1. The VALID Individual Advocacy Service

- 1.1 VALID provides individual advocacy support to adults with an intellectual disability and their families who are considered eligible to receive disability support services within Victoria.
- 1.2 VALID's Individual Advocacy Service:
 - Assists people to address specific issues and challenges they might be facing with either specialist disability or community-based services
 - Empowers people to exercise their rights and be included within their local communities
 - Provides information, advice and referral or direct support and representation, usually on a short term basis
 - Works with people in a non-discriminatory manner
 - Respects privacy and confidentiality

2. The VALID Individual Advocate

Individual Advocates employed by VALID are required to operate in accordance with the Vision, Mission and Aims, as well as the Roles, Methods, Ethical Principles and Guidelines, of the VALID organisation.

3. Vision

VALID is a disability advocacy organization committed to the vision of an Australian nation in which people with disability are empowered to exercise their rights — as human beings and as citizens – in accordance with the Victorian Charter on Human Rights and Responsibilities, the Disability Act 2006 and the United Nations Convention on the Rights of Persons with Disabilities.

4. Mission

The mission of the VALID Individual Advocacy Service is to protect and defend the human rights of people with an intellectual disability, and to champion their rights as citizens to: Community Presence, Choice, Respect, Community Participation and Self Determination.

5. Aims

The VALID Individual Advocacy Service aims to empower people with intellectual disability at a range of levels, from the individual to the systemic. VALID aims to empower individuals with intellectual disability to:

- Exert control and influence over the decisions and choices which affect their lives
- Inform and influence the policies, processes and practices of disability service agencies, governments and other authorities
- Exercise their human rights and citizenship status within their local communities.

6. Roles

The Individual Advocate is required to:

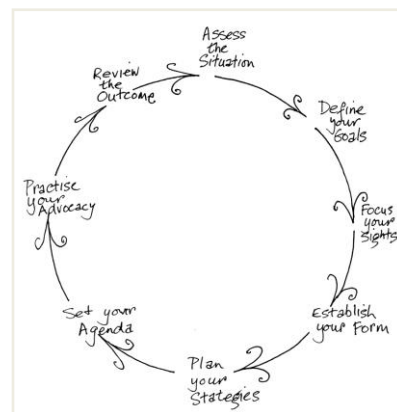
- *Stand Behind* people with an intellectual disability by providing advice, guidance and support that empowers them to assert their rights and achieve their goals.
- *Stand Beside* people with an intellectual disability by assisting them to effectively raise and address their issues, complaints or concerns.
- *Stand Before* people with an intellectual disability by providing representation which defends and promotes their rights and interests.

(Appendix A: To Stand Beside: Advocacy for Inclusion Training Program)

7. Method

7.1 The Individual Advocate is required to be trained in, and to follow, the method defined in the *VALID To Stand Beside: Advocacy for Inclusion Training Program*.

7.2 Each Individual Advocacy case is required to be documented using the VALID Advocacy Action Plan and confidentially reported in the VALID Client Records system.



8. Ethical Principles

8.1 Fidelity and Integrity

The relationship between the Individual Advocate and a person with a disability who is experiencing *vulnerability* and *powerlessness* is a relationship that carries a significant *onus of responsibility*. For many people, the Individual Advocate is the only person who - often in the midst of conflict, confusion and dispute – can be counted on to *independently assert* the person with disability's *views and opinions*, and to stand up for their *rights and interests*.

The *fidelity* of this relationship must be the primary concern of the Individual Advocate, and therefore demands a high level of personal and professional *integrity*.

8.2 ***Avoiding and Resisting Conflict of Interest***

The ability to recognize and avoid, and the courage to resist, potential conflicts of interest is critical to the safeguarding of individual advocacy's fidelity and integrity.

The Individual Advocate must be vigilant in order to:

- Safeguard the person's rights and interests against the interference or undue influence of third party interests – including family members, professionals, service providers, bureaucrats and others - no matter how well-intentioned they might be.
- Recognise and resist *misrepresentation* by third party interests which might conflict with the person's rights and interests.
- Recognise and avoid personal views, opinions or beliefs which might represent a *potential conflict of interest*.

8.3 ***Work collaboratively***

The Individual Advocate is required to operate in good faith with all stakeholders, and to work towards collaborative outcomes wherever possible.

8.4 ***Establish a clear and transparent direction***

Individual Advocates require a clear and transparent direction to guide their advocacy support or representation. There are two broad forms of direction:

- Client Directed – whereby the person with a disability is providing direction and guidance to the advocate, and is thereby authorising their support or representation; or;
- Best Interests – whereby the advocate is acting to protect or defend the person's wellbeing, rights or interests, directed and guided by the principles of relevant laws, regulations, standards, charters and conventions. (See 10.2)

9. ***Client-Directed Advocacy Guidelines***

- At all times, the Individual Advocate should attempt to seek independent direction and instruction from the person they support or represent; i.e. direction and instruction which is *independently informed and independently communicated*, as well as *free of undue influence, free of compliance and free of conflict of interest*.
- A person with intellectual disability's *level of understanding* will often be limited not only by their level of *cognitive impairment*, but also by their *lack of experience* with, or *information* about, the issues being considered. The Individual Advocate should therefore *ensure options and issues are explained or demonstrated to the person in ways which are meaningful*.
- The person's capacity to *understand information* and the *consequences of decisions* should not be assumed; rather the Individual Advocate should check whether the person is *genuinely following* the issues being discussed – e.g. by *gently* asking the person to explain things in their own words.
- The directions given by the person might sometimes be regarded by the advocate as not being in the person's best interests. The Individual Advocate should *address such concerns openly and honestly with the person*, to assist them in understanding the consequences of their decisions.
- The Individual Advocate might sometimes be required to exercise discretion and judgment in balancing the person's right to make decisions which might result in negative outcomes, with their responsibility to protect the person's wellbeing and

interests. *Other than in extreme circumstances – e.g. if a person’s decisions place them in harm’s way - the Individual Advocate should avoid breaching the fidelity of their commitment to the person.*

- Many people with intellectual disability who have limited understanding and experience might be overly compliant with or unduly influenced by the views and opinions of others. *The Individual Advocate should strive to empower the person to self advocate – to effectively assert their rights and live up to their responsibilities - without allowing the advocacy to become another undue or coercive third party influence.*
- Many people with intellectual disability are often susceptible to *undue influence* from a range of *third party interests* with *potential conflicts of interest*. The Individual Advocate should regard with a healthy *scepticism* any attempts to interpret or represent the person’s views and opinions which are not *independently informed* and *independently communicated*. (Appendix B: “Sceptical Thinking”, in ‘Science-Based Practice and the Speech-Language Pathologist’, *International Journal of Speech-Language Pathology*, Gregory I. Lof, 2011)
- Where doubt exists concerning the *reliability* of a person’s communication intent, the Individual Advocate should seek independent and objective *verification*.

9.1 Interpreters and Translators

- Where a person’s language is other than English, the Individual Advocate should arrange for the support of an interpreter or translator – including Auslan where required - in all meetings or correspondence.
- Where interpreter or translation support is being provided by someone already involved with the person – e.g. a family member or support worker – the Individual Advocate should seek to validate that the expressed views and decisions are truly the person’s views and decisions.

9.2 Augmentative or Alternative Communication (AAC)

- Where a person requires assistance or support to communicate their views and opinions, or to express their choices and decisions, the Individual Advocate might support, promote or cooperate with the appropriate use of *augmentative or alternative communication* (AAC) methods.
- The Individual Advocate should strive to ensure that the use of any AAC system aims to promote the *achievement of independent communication* – i.e. communication that allows the person to express their views and opinions or to make choices and decisions, *free of undue influence*.
- The Individual Advocate involved with persons using AAC systems should be mindful of the following advice: “...*some speech-language pathologists are practicing quackery; there are many questionable remedies that lack a scientific basis, they are heavily promoted, and they frequently have accompanying products available for purchase...*” (Appendix B: “Ways to Avoid Being Quacked”, in ‘Science-Based Practice and the Speech-Language Pathologist’, *International Journal of Speech-Language Pathology*, Gregory I. Lof, 2011)
- The Individual Advocate involved with persons using AAC systems should be familiar with Article 12 of the United Nations Convention on the Rights of Person with Disabilities: “Equal recognition before the law: *‘If decisions are made that relate to a person’s capacity to understand, then there must be safeguards against abuse...*”

someone else should only be speaking for you to the extent that it is necessary and for as long as is appropriate. There should be a regular and independent review of the steps taken to make sure that there is no conflict of interest and that the disabled person's rights and interests are properly respected.' In addition, the Individual Advocate should be familiar with: Article 16 Freedom from exploitation, violence and abuse; Article 17 Protecting the integrity of the person, and; Article 21 Freedom of Expression and Opinion, and Access to Information.

9.3 **Facilitated Communication (FC)**

- The Individual Advocate should be aware of the *controversial evidence and issues* associated with the use of FC. (*Appendix C: VALID Systemic Position Statement on the Use of Facilitated Communication, August 2011*)
- Consistent with its Systemic Position Statement on the Use of FC, VALID considers that:
 - The use of *occasional* physical prompting (or facilitation) may be a legitimate accessing (or teaching) strategy which might lead to the development of independent communication *but*
 - Communication which arises from the use of FC without objective validation should not be regarded as having the same degree of reliability as independent communication.
- The Individual Advocate should therefore not accept, without objective validation, communication produced through the use of FC as an adequate basis for receiving direction or instruction, nor as a reliable basis for supported decision-making.
- There are many other AAC methods that have a sound empirical base and can help a client to independently communicate his/her wishes or opinions. When selecting an AAC method, a thorough assessment of the client should be conducted. This should preferably be conducted by a *multidisciplinary team* comprising a speech pathologist (for language assessment) and a psychologist (for cognitive assessment).

10. **Best Interests Advocacy Guidelines**

10.1 **Direct**

Where a person is unable to independently provide – or verify - direction, the Individual Advocate might be required to make *direct representations* that are in their *best interests*. The VALID Individual Advocate is required to exercise discretion and judgment based on a firm understanding of the rights and safeguards that are provided in the Disability Act 2006, the United Nations Convention on the Rights of Persons with Disabilities and the Victorian Charter on Human Rights and Responsibilities, as well as other laws and regulations that might be relevant in particular circumstances.

- *Develop a clear understanding of the person's preferences, needs and interests*
- *Consult with others who might be speaking or acting on the person's behalf*
- *Identify any threats to or breaches of the person's rights and interests*
- *Establish if there is a legally appointed guardian or administrator*
- *Establish if there is anyone currently providing advocacy support in the person's best interests*
- *Establish a clear plan of advocacy action (Refer to TSB method)*

10.1.2 Indirect

Where a person currently has “informal” or “natural” advocacy support – e.g. from friends, peers or family members - that the VALID Individual Advocate considers to be acting in the person’s best interests, *indirect support* might be provided to strengthen and support such advocacy.

VALID will provide advice and assistance to support the “informal” or “natural” advocacy role of families and friends, provided such advocacy is consistent with VALID’s Vision, Mission and Aims, and is consistent with the principles of the Disability Act 2006, the Victorian Charter on Human Rights and Responsibilities and the UNCRPD.

Appendix A

(From “*To Stand Beside: The Advocacy for Inclusion Training Manual*”)

Stand Beside

The preferred form of advocacy is *to stand beside* - i.e. with advocate and person with a disability in partnership, possessing shared goals and a shared purpose. This involves a relationship of mutual trust and understanding, with the advocate providing whatever ‘moral support’, technical assistance or reinforcement is necessary to enable the person with a disability to assert their rights effectively and with confidence.

Advocacy provides ‘stand beside’ assistance to assert the rights and interests of people with a disability. This can involve:

- accompanying a person or group in meetings
- prompting and reinforcing the expressed views and interests of a person or group
- assisting in clarifying goals, developing strategies and advocating the views and interests of a person or group

Stand Behind

Standing Behind refers to advocacy which supports people with a disability to speak up for themselves. For people with a physical or multiple disabilities, such support might involve providing an individual with the appropriate electronic or physical aid. For people with a sensory disability, such support might come from the provision of a brailing machine, a white cane, or a signing interpreter. For people with an intellectual disability such support comes typically, but not exclusively, through the provision of self advocacy support workers. Their role it is to support people with an intellectual disability to understand an issue, to develop their opinions and goals, and then to articulate or express their views. This can also be the role of teachers, parents, care and support workers, who are also often involved in empowering people with an intellectual disability to speak up for themselves. This is a legitimate and necessary role, but Standing Behind a person with an intellectual disability also demands that the supporter recognises and addresses the potential conflicts of interest that might arise between their support role and other roles which they might play.

Advocacy provides ‘stand behind’ support to assert the rights and interests of people with a disability. This can involve:

- providing training in self advocacy and advocacy skills
- supporting self advocates to speak up
- advising people with a disability and families on issues & strategies
- providing information which might enhance the advocacy of people with a disability and their supporters

Stand Before

Standing Before refers to advocacy which is representational, and is particularly appropriate on behalf of people who are unable to advocate effectively on their own behalf. It is perhaps the most vexed of advocacy forms, because there is never any shortage of people who believe they have a legitimate role to play in representing the interests of such people.

Standing Before, as the term implies, involves defending and shielding vulnerable people from harm and danger; it also implies and involves speaking for and championing their interests; it also implies, but may not always involve, a close alliance or relationship between the advocate and the vulnerable person.

Advocacy provides 'stand before' representation to assert the rights and interests of people with a disability. This can involve:

- speaking or acting on behalf of people who are unable to assert their own views and interests
- speaking or acting as the nominated representative of an organization or group
- speaking or acting as the legal representative of an individual or group

Appendix B

Excerpts from 'Science-Based Practice and the Speech-Language Pathologist,' International Journal of Speech-Language Pathology, Gregory I. Lof, 2011

'Sceptical thinking

In order to not be quacked, it is necessary to be a sceptic. Sceptics are people who have a questioning attitude or have some degree of doubt regarding claims that are elsewhere taken for granted; by doing so they are practicing scepticism. According to information found on the skeptics.com (2010) webpage,

Scepticism is a provisional approach to claims. It is the application of reason to any and all ideas – no sacred cows allowed. In other words, scepticism is a method, not a position. Ideally, sceptics do not go into an investigation closed to the possibility that a phenomenon might be real or that a claim might be true. When we say we are 'sceptical', we mean that we must see compelling evidence before we believe.

Sceptics have a difficult balancing act to perform: on the one hand they must be open to new ideas, no matter how bizarre or counterintuitive – while on the other hand they must have a ruthless scrutiny of all ideas, old and new. As Dr Michael Shermer of the Sceptics society (Sceptics.com, 2010), points out, "Some people .. confuse sceptics with cynics and think that sceptics are a bunch of grumpy curmudgeons unwilling to accept any claim that challenges the status quo. This is wrong". Sceptics must be willing to test all claims, no matter how peculiar sounding they may be, because the assertion may hold promise for success. However, upon stringent investigation if a claim is found not to be valid, then it must be abandoned.

One of the areas to apply appropriate scepticism was identified by Lum (2002), who provided insightful cautions about packaged speech-language pathology therapy materials and programs that are increasingly available for purchase. These pre-packaged therapy resources "...constitute a growing market but there is no process in place for vetting the quality, relevance and effectiveness of the product ..."

'Ways to avoid being quacked

Quackery is a type of pseudoscience that can be defined as any practice or remedy that has no compelling scientific basis. It includes questionable ideas, product, and services, regardless of the sincerity of the promoters (Barrett, 2008). A quack, who practices quackery, is NOT a charlatan (a.k.a., con artist, flim-flam man, snake oil sales-man); charlatans are people who pretend or claim to have more knowledge or skill than they actually possess, know that their skills are not real, and use deception to obtain money, fame or other advantages. Shermer (2002) points out that most people are not intentional deceivers, but rather normal people whose critical thinking has gone wrong in some way.

Shermer (2002), in his book *Why People Believe Weird Things*, has an entire chapter devoted to describing 25 fallacies of thinking that can lead people to believe "weird things" and make them practice some type of quackery. An expansion on a few of these erroneous beliefs that are pertinent to the practice of speech-language pathology will be presented later.

The reason to explore such fallacies is because some speech-language pathologists are practicing quackery; there are many questionable remedies that lack a scientific basis, they are heavily promoted, and they frequently have accompanying products available for purchase. Because of the numerous alternative treatments in every area of speech-language pathology, clinicians need a way to determine if a procedure or product is worthwhile.

Barrett (1997) offers 10 suggestions on how to avoid being quacked; five of these are especially pertinent to practitioners (listed in Table I).

Table I. Five things to help clinicians avoid being “quacked” (adapted from Barrett, 1997)

1. Be aware that quackery seldom looks outlandish
2. Be wary of pseudoscientific jargon
3. Be sceptical of anecdotes and testimonials
4. Be sceptical of claims of effectiveness of a treatment for a large range of unrelated problems
5. Don't let desperation cloud clinical judgement

Barrett's (1997) first suggestion is to recognize that quackery seldom looks outlandish. Promoters of fad treatments often follow somewhat standard therapeutic procedures, but with modifications (e.g., using well-established AAC devices but applying them to facilitated communication). Also they may use scientific sounding terms and may quote/misquote scientific references that makes it appear as through the therapy is mainstream.

The second way to avoid quackery, therefore, is to be wary of pseudoscientific jargon. Clinicians must be sure that the terms used are following accepted standards and are not invented so that they appear to be scientific.

Third, clinicians need to be sceptical of anecdotes and testimonials. Testimonials are not science; they may be interesting and compelling, but they cannot be used to determine treatment effectiveness. Be cautious if only personal narratives are used to support a treatment's benefits.

Fourth, clinicians need to be circumspect of claims of effectiveness for a single treatment that is applied as a wide range of unrelated problems (e.g., Auditory Integration Training/Therapy [AIT, 2010] claims to help all types of disorders of hearing, autism, attention deficits, dyslexia, and more). Because there is no such thing as a “cure all”, clinicians should rely on the adage that *if it sounds too good to be true, it probably is not true*.

Finally, clinicians cannot let desperation cloud clinical judgement. Frequently therapists, clients and parents are desperate for positive changes, but this desperation causes some to forgo sceptical thinking.'

Appendix C

Appendix D: VALID Systemic Position Statement on the Use of Facilitated Communication, August 2011

<http://valid.org.au/FCPosition>