

*family*

A D V O C A C Y

## **The Seduction of Care: the lure of the special and the expert**

*Ric Thompson*

Let us be aware of the possibility of ‘seduction’ when we find ourselves in the presence of specialists, experts and special programs. This paper is not an attack on the expert, specialist and special program but does caution against a potential false belief in them.

Many years ago whilst holidaying in Melbourne, I experienced for the first time, a major seizure, as a result of a condition known as Adult Onset Epilepsy. This sudden event resulted in me, personally, feeling a great sense of vulnerability and uncertainty about my future and, in particular, my future health status. After extensive tests I returned to my home town of Townsville, where I was to meet my supervisory neurologist.

My appointment was quick and efficient, comprising of a medical check up and cordial discussion until, at the moment of invitation to retire, I pulled out my notebook and proceeded to present a number of questions for his valued consideration and comment. I was met with rolled eyes. I proceeded to present the prepared questions and received responses that I was cautiously satisfied with. I was now able to proceed with my life. My questions had been addressed, but without doubt, within an environment of professional distance.

Ten years later, after having been taken off the prescribed medication, I experienced a further seizure resulting in a return to my neurologist. It was late on a Friday afternoon. I was greeted with respect and expressions of genuine concern. My specialist looked so tired and exhausted. He in fact needed a doctor! A script was quickly written out, a repeat of my past medication requirements. I happily accepted the script, until my partner asked, “Doctor, if you were in Ric’s position, what medication would you prescribe for yourself?” Without hesitating, an alternative medication was proposed. The significant benefits, such as reduced side effects etc were discussed as well as the significant increase in cost. My partner thanked him for his concern but quickly reminded him that the issue of cost was one for us to consider and was not his responsibility. A new script was written and to this day, although not wishing to be bound to the daily ritual of taking medication, thanks to the intervention of my partner within an environment of professional expertise, I was the recipient of a good outcome. There is a need for us to have both safeguards and supports around us in the presence of the expert, specialist and professional.

So what do we mean by the term expert? Expert (n) is defined as a person with specialist knowledge or ability, who performs skilfully. The specialist(n) on the other hand is devoted to a particular occupation or branch of study or research. The term 'special' (adj) is defined as better, greater or otherwise, different from what is usual.

With this in mind, it is important to emphasise here that there are legitimate and valued roles that the expert and the specialist may fulfil.

The expert and the specialist introduces specialist knowledge, skills and the ability to identify needs, that may result in positive outcomes. When I visit the dentist I am pleased that I am not calling upon my plumber to carry out the work. Likewise, when faced with a complex and often technical dilemma I may call upon the expert or specialist to assist me in my understanding through the provision of valued third party advice. Finally, daily in the media, we hear or read of significant advances, especially in the area of medicine, as a result of the expert or specialist focussing his or her attention on further exploration and or investigation into the unknown.

Despite these significant advantages, we may over time, experience some of the non-legitimate roles of the expert and the specialist, such as:

- the holding of negative assumptions about us or others known to us
- the holding of power and in particular, the holding of information and, finally
- where the expert and the specialist determines that they should hold the position of principal decision maker.

The differing perspectives between the expert, the specialist, the special program and the community, is captured clearly in the following chart.

<u>Communities</u>	<u>Expert</u>
<b>Assumptions</b>	<b>Assumptions</b>
<b>Person</b>	<b>Client/patient</b>
<b>Individual</b>	<b>Bigger problem</b>
<b>Gifts (+)</b>	<b>Needs (-)</b>
<b>Opportunities</b>	<b>Services</b>
<b>People</b>	<b>Programs</b>

In particular, we see the expert defining people as clients or patients, who must be seen as part of a bigger problem/group. This is reinforced by the presence of defined deficits, requiring special services or programs, defined by way of specialist language. These services or programs are offered by specially trained people whose work is evaluated by other specialists, who are members of the same team.

Meanwhile, community members may present the same situation in a somewhat different manner. They may see the individual as a person, who brings with them their unique individuality, reinforced by their equally unique gifts, talents and contributions, which belong within the countless opportunities that exist within community, surrounded by other people rather than services and human service programs.

With such a differing view of the world, how can we assist community members to negotiate positive outcomes for either themselves or others known to them?

Perhaps there is a need for us as citizens to view ourselves from a different perspective - from the perspective of 'expert witness'. The term 'expert witness' is one that is used within the legal world to refer to people with a deep understanding of a particular area, who share their expertise, personal experience and knowledge and assist in both defining the situation before them, as well as in hypothesising about future possibilities. It would appear that both individuals with a disability and their families may benefit by re-defining themselves within the world of the expert and the special as 'expert witnesses' to their own daily life circumstances.

So if we are to define ourselves as 'expert witnesses' what are we able to call upon to assist us in this role?

I would like to introduce a most helpful tool which, for the purpose of this paper, I have re-defined as the 'Pay Attention Model' (\*). This model assists us, not just in our understanding of what is happening about us, but also what may happen to us, in the event of being participants in a new life experience.

This model, developed by Professor Wolf Wolfensberger, from Syracuse University New York, under the title of Model Coherency Analysis/Construction, seeks from us answers to the following questions.

**Who** are the people and what are their needs?

**What** is the program or service being offered and how relevant is this to the needs of the person?

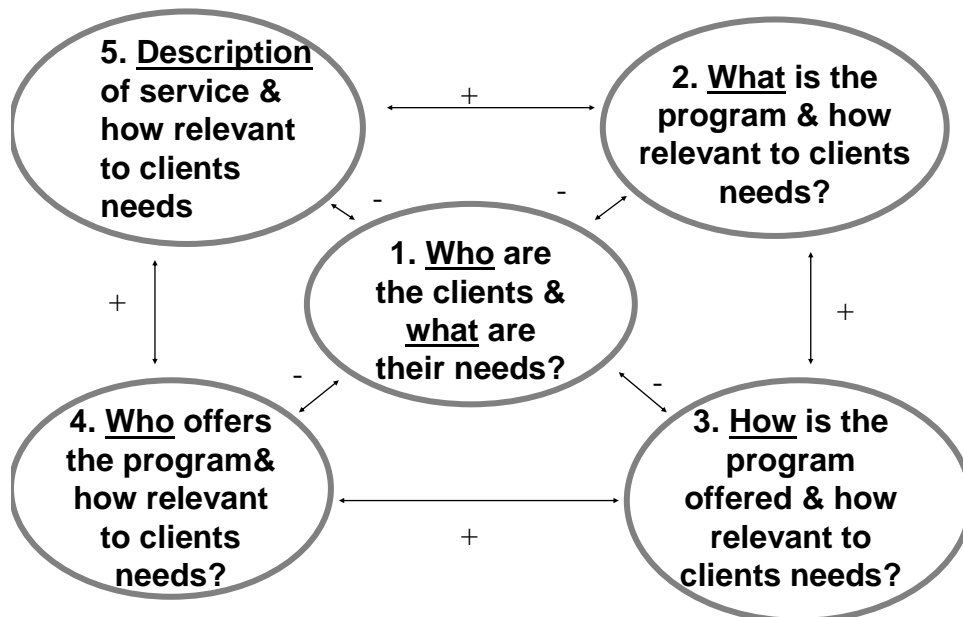
**How** is the program/service offered and how relevant will this be to the needs of the person?

**Who will offer** the program/service and how relevant is this person's skill, knowledge, understanding and experience to the needs of the person?

And finally, what will this program/service **look like** and will it or does it look like a service/program that will (or does within other parts of the community) meet the needs of the person?

These fundamental questions can be applied to any basic enquiry as set out in the following diagram:

### The Pay Attention Model



The 'Pay Attention Model' asks of us (and others) the following question:

***Is the right program/service  
being offered to the right person  
in the right way  
by the right people  
and consistently so?***

It is important to highlight some significant observations when we reflect on this diagram. First, as you will notice, the model captures the fact that the individual (in our case the individual with a disability) and their needs are central to the process of our enquiry or investigation. It may be said to be another example of person centred planning. Secondly, the diagram by its interconnecting lines, proposes that there is some sort of connectedness between all of the sections or key questions being asked. This is where Professor Wolfenberger would draw our attention to the concept of coherency. Professor Wolfenberger's argument is that it is not until all these components of the model are working in harmony together that we will get the most effective or powerful outcome for the individual. I prefer to view the circles within the model as cylinders of a motor vehicle and, unless

they are all working in harmony together, we will not get the best efficiency, effectiveness and reliability.

Finally, when we first come across a newly proposed program or a service (reflected by looking at the outside four circles of the model) we may be at risk of being seduced by what we see or what we hear, not by the relevance of what we see or hear to the central person in the middle. Sometimes, we may be led to believe that something is good, is run well, by good people and it certainly looks good (and can be illustrated by placing positive symbols '+' on each of the connecting lines) but when we look closer we may find that what we see and hear may in fact have little relevance or truth in meeting individual's needs (captured by way of negative symbols '-' 'see diagram).

Through being invited to consider these key questions, we are further invited to ask of ourselves the following questions.

When we think, see and hear of what is being proposed or presently offered to our son or daughter with a disability, what are the assumptions that are driving this response? What value does this place on the individual concerned? What impact will this program/service have on how the individual sees him or her self, how we may see him or her, and how the wider community may perceive the individual person.

In addition, the question of seriousness is important here in that whatever is being proposed or offered must have clear indicators of seriousness and thoroughness if what we are seeking is to in fact occur. For example, if we wanted to introduce our son or daughter to a local athletics program, we would expect to see before us an athletics program that is a real and proper athletics program, run at an athletics track, in the presence of other athletes, who present themselves looking like athletes, being coached by a trained and competent athletics coach and having their performance measured.

The question of leadership is equally important. Is the leadership being offered appropriate, competent and reliable with the capacity to both invite and involve others in the meeting of the individual's needs?

This paper invites you, the reader, when considering something that is being offered to you by programs or services, to take the opportunity to pause and reflect by asking of yourself the following:

***Is the right program/service  
being offered to the right person  
in the right way  
by the right people  
and consistently so?***

If that hasn't got you thinking enough, you may wish to proceed further by asking of yourself the additional questions:

***What are the dominant assumptions that drive this program or service?***

***What evidence of seriousness is present in the program or service?***

***What reliable and consistent leadership is present?***

These questions invite us to pause and reflect (even better in the presence of other people) and in so doing, enable us to 'pay attention' to what is really happening around us.

Germaine Greer captures the importance and value of pausing and of reflection when she says, "Every thing that is, could be otherwise".

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