

**Queensland Community Care Conference**  
**7 October 2005-10-02**

**Ian Boardman**

**Public Advocate – Queensland**

Delivered by Beverley Funnell, Senior Research Officer- Office of the Public  
Advocate

**Quality Supports for People with Complex Needs and Challenging  
Behaviours or – ‘the pointy edge of compassion’**

Good afternoon. Thank you for the invitation to speak to the Conference today.

With your forbearance I plan to do the following

1. Take a somewhat offbeat view of ‘challenging behaviour’ to highlight the fact that like beauty – what is deemed to be challenging, in many respects is in the eye of the beholder.
2. Spend a little time describing some characteristics of ‘challenging behaviour’ and its impact on individuals and those that care for and about them.
3. Outline the advocacy work the Office has undertaken in this regard and particularly our approach of forging alliances between assumed unlikely parties.
4. And to finish I want to return to the subjective nature of judgements about ‘challenging behaviour’- and to posit the value of listening to behaviour with humility- just in case there is something important for us to learn, and not just about the people we serve but about ourselves as well.

Acknowledge traditional custodians

As a preface to all that I want to acknowledge the traditional custodians of the land on which we gather. As one of my Indigenous colleagues says, let us tread softly for it is their dreaming we walk upon “.....

Dreaming in the aboriginal tradition – which more accurately means stories, legends are important as conveyers of meaning, wisdom and values. Our aboriginal brothers and sisters challenge us as to look at things in a different way – what the land means to us- the importance of place and a sense of place, our connections with our family and kin, our sense of identity and our spirituality.

Although the dominant values of our society are far removed from these things they are still powerful notions as they tap into some deep longings and needs we have for meaning and fulfilment.

Notions of place and belonging remind us how our modern society with its focus on economic growth and individualism increasingly feels more like an economy and less like a society- and less and less like a civil society. This provides the terrain for the trampling of dreams – both in the aboriginal and the aspirational sense of hopes and desires.

Many social commentators speak of a loss of social capital. This refers to the wide variety of quite specific benefits that flow from the trust, reciprocity, information and cooperation associated with social networks. In other words the people we know and are connected with and the inclinations that arise from these networks to do things for each other.

The consequence of the loss of social capital for community and associational life, and particularly on the capacity of communities to care for their own, let alone for the ‘challenging other’, is glaringly obvious. In a former era of human service it was believed that segregation and congregation of people with disabilities was a necessary and acceptable model of service. It still is so it seems for our elderly people. It is interesting to contemplate the cause –effect dynamic of removing responsibility from communities to formal institutional models.

#### Challenging behaviour – often very subjective

What is deemed challenging in our society is, to some extent, subjective. Accepting that we are socialised within a particular culture to have some shared understanding and responses to overt behaviours such as aggression, cruelty and property damage, there are still varying degrees of tolerance which reflect individual values and perspectives.

From the perspective of people who are powerful and well resourced the ‘behaviour of concern’ is rarely their own. When the bureaucrats created their child removal policies back in the 1930’s they certainly didn’t see their actions as problem behaviour. The problem behaviour according to Cecil Cook (NT) and A.O. Neville (WA) in the late 1920’s and 30’s was that the population of indigenous people, rather than dying out as anticipated, was at risk of remaining, even expanding due to birth of mixed race children.

A behaviour that is always seen as challenging is that of criticism. I guess we are all in the same boat here – no-one with the possible exception of a masochist likes criticism. Those of us involved in the human service sector want to believe that we mostly do the right thing by the people we serve or at least that we have honourable intentions and when we don’t we certainly don’t want that to be discovered - and we certainly don’t want our failings/shortcomings the subject of public attention.

The result of this is that criticism is generally unwelcome. This makes it very hard for a ‘watchdog’ agency which has as one of its function a responsibility for monitoring the performance of Government and service providers. My Office which has a statutory role to do with promoting the rights of adults with a decision-making disability and promoting their protection and interests inevitably involves pointing out to both Government and non-Government agencies how they might improve their

performance. No matter how diplomatically this might be put – a watchdog agency such as mine will often be accused of being unfair or at least not understanding of the constraints that agencies operate under.

My Office is not alone in this regard. Many parents/carers also report their behaviour of raising issues/complaints about service quality is also very challenging and seems to elicit a range of responses that are clearly intended to discourage further repetitions. Perhaps it is viewed as attention seeking behaviour, and if concerns are ignored then the undesirable behaviour will disappear. Showing any real interest in the concerns raised may only encourage more complaints. Who knows what assumptions are operating? Complaint systems are now virtually mandatory; there is considerable rhetoric supplied about how Government and service providers welcome feedback from service users. The actual experience of many complainants, however, is to the contrary.

In giving these somewhat offbeat examples I want to illustrate that at a fundamental level we respond to people who challenge us in similar and predictable ways – a clear pattern emerges which derives from a ‘shoot the messenger’ mentality. Whether that be the

- Public Advocate,
- an individual advocate attempting to speak or act in the interests of a vulnerable person,
- a parent, sibling other family member raising a concern with a provider,
- an employee speaking up about an abusive practice she/he has witnessed,
- or vulnerable adult Queenslanders living with an intellectual disability, a psychiatric disability, an acquired brain injury or one of the dementias who exhibit behaviours that cause concern to those who care about them and those who care for them.

Perhaps you have never thought about these people- the people you serve as messengers?

These similar and predictable ways of responding that I have referred to include ignoring, separating ourselves- putting distance between ourselves and the person who exhibits the behaviour of concern; intimidation, isolation, retribution, castigation, counter-attack- all forms of ‘shoot the messenger’ rather than hearing, considering its meaning and responding to the message.

The personal impact on those of us who speak out or align ourselves with the least powerful may be quite significant in the sense it is likely to deliver hurtful and wounding consequences for us. At least it is bound to be disappointing and frustrating. It is well documented that whistleblowers pay a high price for revealing serious inadequacies in systems and services. Typically whistleblowers experience harassment and punishment. Their experience proves to be costly to themselves in physical, financial and emotional ways.

Those of us who are involved in advocacy think we understand the theory associated with it. We acknowledge that advocacy always has a personal cost yet when it happens to us there is a sense of injustice – even outrage. However for people who live in a heightened state of vulnerability, those who are already marginalised in

society by virtue of a disabling condition, particularly one of a cognitive nature the consequences for them of their ‘challenging behaviour’ may be far more devastating.

## **Definition**

Let me clarify what is meant by this term ‘challenging behaviour’. A fairly straightforward definition is provided by Eric Emerson, a UK based researcher

*Behaviour of such intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy or behaviour which is likely to seriously limit or deny access to the use of ordinary community facilities.*

Some examples include aggressive, self –injurious behaviour, screaming, constant swearing and shouting, dangerous road behaviour, throwing of dangerous objects and inappropriate overt sexual behaviour.

People using these behaviours are sometimes described as having ‘high support needs’ or ‘complex needs’. I find it more helpful to perceive them in the first instance as people with unmet needs. Whatever the label they attract they are typically not easy people to support.

Such behaviours are likely to limit the person’s ability to participate in daily life and to enjoy potentially life-enriching experiences. The behaviour of some people may be so disruptive and harmful that families and services may have extreme difficulty in meeting their needs-or even understanding what their needs are.

It is important to acknowledge that there is, within this group, a small cohort of people who may present a real danger to the community. There will be those who will require more restrictive support arrangement due to the harmful nature of their behaviour. While this speaks to the limitations of our collective practice wisdom, a critical systemic issue is that those arrangements should be constituted in such a way as to maximise opportunities for liberty and to minimise the risk of neglect or abuse.

To quote Sue Pieters-Hawke who spoke to us this morning- ‘We all give lip service at least to the idea that compassion, caring for each other, is to be highly valued. But we are talking here about people and situations that require more. This about the pointy edge of compassion and support requirements.’

The impact of challenging behaviour on those who care for and about the people can be upsetting, frightening and sometimes even harmful. However the impact of the behaviour on the people themselves is not a ‘picnic’ either. The consequences for them are serious and will include at least one but most probably most of the following:

- They will be blamed – (akin to shoot the messenger) – for many people behaviour is used as a form of communication – with a significant cognitive impairment verbal communication is also usually impaired –no surprise really when we remember the close association between thought and language.
- Have a very poor reputation – even the gifts a person may have not recognised

- Social rejection
- Seen only as a client not as a person
- Loss of opportunity for enriching life experiences
- Subject to physical and/or chemical restraint
- At risk of containment legally or otherwise
- Being socially isolated, without friends
- Loss of relationships
- Brutalisation to the point of death
- At great risk of not having fundamental needs for love, belonging and acceptance met
- At risk of being grouped with others who are also similarly challenging
- Person assumed to be more disabled than they actually are. Eg autism – assumptions made about person’s intellectual ability resulting in limited educational opportunities to learn to read and write.

### **What causes ‘challenging behaviour’?**

It is now clear that people with ‘challenging behaviour’ are not a homogeneous group. The term has been applied most frequently to citizens with an intellectual disability however people with other forms of impaired decision-making may also exhibit behaviours which cause concern to those who care about them and for them.

The causes can usually be attributed to physiological, neurological, psychiatric or environmental factors. In respect of the latter the behaviour may emerge as a response to their own life stories, a reaction to experiences of abuse, isolation, rejection, frustration, or a lack of support at earlier stages of development. For some people the people can be attributed to their experience of living in an institution. In some cases the actual cause may not be known.

In circumstances where an autistic spectrum disorder, an acquired brain injury or an intellectual disability limits a person’s ability to communicate verbally behaviour can be used as a form of communication.

Dementia as we know is a progressive, organic neurological disorder that is characterised by memory impairment, cognitive decline and changes to personality. Behaviours of concern generally arise because of the impact of the dementia on the person’s ability to interpret, understand and react to the world in which they live. These may include:

- Verbal aggression- associated with confusion and anxiety
- Disinhibition – socially inappropriate behaviour
- Repetitive actions or questions
- Resistance to care
- General restlessness and agitation

### **Acquired brain injury**

People who have acquired a brain injury through an accident or illness are at risk of developing a behaviour that will make their acceptance and participation in community life more difficult. They may, for example become physically or verbally

aggressive, use socially inappropriate behaviour due to a reduction of inhibition. All of the above arise as a direct result of the injury that was experienced.

## **Responses to people who are seen to be challenging**

I have already outlined the consequences to people of their challenging behaviour. These wounds largely occur as the result of the way people are responded to. Perceptions held of them are usually so negative that they are unlikely to receive an abundance of understanding, sympathy or concern from the majority of community members.

This group of people is also highly vulnerable within the service system by virtue of the difficulties that many service providers have in serving them. A custodial approach often inadequately substitutes for a program of intervention which assumes the capacity for learning and development.

Recent approaches to service delivery in Government and Non- Government sectors heightens the risk that individuals will be objectified as commodities, as 'bed' or 'places' within a market driven service environment. This in itself may contribute to shaping impersonalised and even dehumanising practices.

Implicated in these deficiencies is a loss, over the past few year of technical know-ho in service design and delivery.

## **How should we respond?**

As a human service sector we need to leave behind the erroneous myths and incorrect assumptions about so called challenging behaviour. Examples of these assumptions include the belief that people are mad or bad; that problem behaviour is aberrant; that challenging behaviour is usually attention seeking; that people with strange behaviours cannot live in the community; that adults with seriously challenging behaviour cannot learn new ways of functioning and that people with similar challenges are best grouped together.

When assumptions cannot be proven correct or incorrect – the wisest path is to follow the 'do no harm' principle or adhere to the criterion of the 'least dangerous assumption'. It is preferable to make the most positive- least harmful assumption when there is lack of certainty about the effectiveness of competing interventions.

It is important that we surrender a 'blaming mindset' that defines the person and often the family as the problem. Within this mindset there may be little acknowledgment of the shortcomings of the service provider, little recognition of inadequate practice wisdom, nor of the role that the environment plays.

There is now substantial evidence to suggest that many people who have been labelled as having 'challenging behaviours' and/or 'very high and complex needs' can learn to modify their own behaviour when skilful and compassionate human service interventions are brought to bear. This is not to suggest that human services can fix everything – however a quality intervention may identify what the person's unmet needs are and take action to address this. This may include solutions that are outside

of formal services. For example, assisting someone to reconnect with a parent or sibling or supporting the development of a freely given relationship may address, for some people, a deep emotional need for acceptance and belonging. For other people highly technical interventions and support will be required.

Some of these interventions may be financially costly in the short term but they can lead to an overall reduction in costs over time.

For those many who use behaviour as communication an appropriate response will be to discover and hear the message that is being communicated. This is not always easy.

For people with dementia although their behaviour changes are related to changes in the brain the intensity and frequency of concerning behaviour can be modified. This may be achieved when family carers or service provided carers receive support and guidance from competent professionals/practitioners who work to establish a mutually respectful relationship. There is a National Dementia Behaviour Advisory telephone service operated by skilled practitioners who are physically based in Glenside, South Australia.

Other people who, because of the nature of their disability have 'hard wired' ways of viewing their world that are not amenable to change, can thrive in physicals environment that are modified to suit their needs. For others the research needed to guide policy and practice is yet to be done.

## **What is required – what needs to happen?**

This is an appropriate point at which to refer to the work my Office undertaken in respect of the issue of challenging behaviour. Firstly it is necessary to establish the Office's legitimacy in this matter.

### **The Role of the Office of the Public Advocate (OPA)**

The position of Public Advocate was established in recognition of the heightened vulnerability of people with impaired capacity for some decision making matters. It is the statutory function of the Office as set out in section 209 of the *Guardianship and Administration Act 2000*, to protect the rights and promote the interests of adults with a decision-making disability. Another related function is to promote the provision of services and "encourage the development of programs to help the adults reach the greatest practicable degree of autonomy".

My Office has spoken and written about this issue at length. We have made submissions to Government; we have sat on advisory groups; we have spoken at Conferences. It is instructive that now in the last month of my tenure I am still speaking to this issue. The critical system failure in relation to challenging behaviour was the first issue I pursued with Government when I took up the position of Public Advocate in January 2001. We have always acknowledged that in many instances our advocacy would be required over the long term. This is certainly true in regard to this systemic issue.

To guide the work of the Office we developed a framework based upon a nine component matrix in which policy and practice can be located and validated.

The framework is based on three interrelated elements operating at three different levels. These are:

**Principles**

**Resolve**

**Competent address of needs**

At the level of :

**Supports and interventions for an individual**

**Agency /organisational practice**

**Service system**

A full description of this framework can be found in the Office's first Issues Paper published in June 2004, titled "Opening Doors to Citizenship. Quality supports for people who have complex unmet needs and who currently challenge the capability of the service system."

As an example of the application of this framework I will speak briefly to 'the competent address of needs' at an individual level which I think will be of relevance to many of you here today who within your organisations strive to ensure that the support you provide meets the needs of the individuals you serve.

Initial work should focus on key aspects of the person's life, with a view to making adjustments to achieve what is workable and meaningful for the person. Services may become so focussed in responding to the 'problem' that they may fail to ask some basic questions. These are:

- Who is the person?  
What is the person's history, their formative life experiences, their idiosyncratic characteristics and personality, the impact of disability on their life, their family life relationships and experience of the service system?
- What important needs are unmet for the person?  
Given a full range of options, what would this individual change about their life? What has changed about this person's life that may not have been in accord with what they would have chosen?
- With whom does this individual have meaningful relationships?  
What is the quality of those relationships?  
Who loves this person and whom does this person love?

Other important considerations that could inform an action plan include:

- Health care – is this adequate? There are numerous accounts of signs of ill health that have not been recognised. Examples include people with a history of ear infection and subsequent chronic or acute pain that goes unnoticed or unattended, yet which can lead to behavioural outbursts.

- Power and control issues within the existing care and support environment. There may be an absence or unreasonable restriction of choice in the timing and substance of fundamental daily activities such as eating, drinking, bathing, and appropriate contact with support staff.
- Is attention paid to the appropriateness and quality of support strategies that are used by staff?
- Is there an understanding of the predicament that people without efficient verbal communication face in having their needs met?
- Lives may be filled with meaningless activities that do not reflect the interests of the person. Boredom is often a contributor to the onset, escalation and maintenance of challenging behaviour.
- Does the household environment reflect the person or people who live there? There may be a barrenness that robs an environment of the personal and comfort qualities associated with a sense of 'home'. Accommodation that is meant to be a home might more often be perceived solely as a workplace.
- People may be forced to live with housemates with whom they lack compatibility and who may have competing needs.

### **Systemic issues often reveal critical gaps in our human services**

Our work in collaboration with many individuals and agencies in the sector has identified a number of critical service system gaps or inadequacies that unless addressed will continue to have serious consequences for individuals, families, service providers and those who directly support those labelled as having 'challenging behaviour'.

The following gaps have been identified. Some overlap between separate items is assumed:

- a coherent policy framework
- a plan/agenda for the future
- policy development informed by evidence and positive values
- expertise embedded across the State and across systems
- cross sector leadership
- acknowledgment and address of the impact of poor service delivery practice
- ongoing research embedded in practice
- research translation and dissemination
- greater understanding of the contributing, causative and preventative factors
- human resource investments – training, development and retention
- early intervention (early in life and in presentation)
- development of new service models underpinned by positive values and informed by sound evidence
- practice advice and support to the field
- strategies to address the small but extremely challenging cohort of serious re-offenders

### **Investment in people**

The most critical ingredient in a responsive, effective system is the people factor. Since it is also the biggest financial cost for the service system there is a strong business case in ensuring that there is a strategic approach to human resource

utilisation. This is about aligning recruitment, selection, orientation training, support/supervision and ongoing development to program objectives.

## **What has the OPA done about these issues?**

The March 2005 meeting, the Public Advocate's Reference Group focussed on appropriate service responses to the complex support needs of citizens who are characterised as having 'challenging behaviour'. The Reference Group developed a work plan that the Office would implement and sought undertakings that the Reference Group would reconvene within six months to evaluate progress.

The core of the work plan was a series of separate meetings with service providers, academics/practitioners and community representatives in which the issues could be more thoroughly explored. In particular, participants were asked to comment on the recommendations of the Office's first Issues Paper (*Opening doors to citizenship: quality supports for people with intellectual disability who have complex unmet needs and who currently challenge the capability of the service system*). These three meetings had been held by end June 2005.

The Office collated the material for resubmission to the Reference Group when it reconvened in August 2005. The purpose of that meeting was to develop an agreed approach to submit to the Queensland Government.

There was a united view that the area of 'challenging behaviour' was an important systemic issue that is overdue for close examination.

The groups acknowledged:

- the loss of expertise in behaviour support from the disability field
- that past responses for this cohort have often been piecemeal and not sustained over time
- that to embed service excellence and ensure ongoing reform leadership and investment is required.

On 4 August the Public Advocate brought together over 50 representatives including service providers, government officers, academics/practitioners and community/family representatives to develop a position to take to Government. Commitment was gained from over 20 individuals/organisations prepared to work together with Government to explore options to address this issue.

The August Forum Group proposed a way forward which was:

- Meet with Government – a letter to go to the Premier requesting a meeting with a Delegation from across the sectors (academia., service providers, advocacy, parents/family and the area of psychiatric disability).
- Establish a taskforce with combined cross-Government and cross-sector membership to jointly design an appropriate strategy to move forward
- Report back to Government

## **Unlikely Alliances**

One of the important features of the process the Office employed to build consensus and commitment to progressing this issue was the strategy of forging unlikely alliances. This approach has characterised a great deal of the successful work the Office has undertaken during its first five years. The forum brought together individuals and agencies that serve people with impaired capacity but who typically don't work together. Furthermore some of these agencies assume that they have nothing in common with other groups. However when the common ground is identified diverse perspectives can come together and identify what they can agree to support.

## **Conclusion**

As I indicated at the outset I want to return to the subjective nature of perceptions of 'challenging behaviour' and highlight the importance of 'listening' to behaviour with humility. I invite you to take a journey with new glasses so as to be able to take a fresh look at things. I encourage those of you who find the issue of challenging behaviour all too hard, to look at people as messengers who have something to tell us about their lives, about their hopes and dreams but also something to tell us about ourselves.

This won't make things instantly easier or better but it may help us to stand alongside and be with people in what they are experiencing and what they are trying to tell us. It may help us not to blame the person but to have resolve (determination) to remain steadfast and as useful as we can possibly be. However in our various roles in caring for people in the community we will need to gain the required understanding and skills. For those who manage and lead it is essential that this is understood and facilitated.

For those who work at the systems level there will be related but different challenges to deal with. Remember the power of unlikely alliances- the potency in finding the common ground and building on it collaboratively. This is relevant in approaching a whole range of important issues- not just the one that I have spoken about today.

We are all walking along a road that has many turns and corners. In our walking let us be careful not to trample on the meanings, hopes and dreams of the more vulnerable in our communities. Remember that some corners may produce unexpected events. Some of you here may become parents or grandparents to a child with a disability; someone's son may have a serious trauma resulting in a brain injury; your mother or father may develop dementia and it is likely that some of us here will develop dementia as we age.

It is possible that if we live long enough we will all require assistance and support to get through the day. It is even possible that some of us could become quite challenging?? Let us not become the slave who makes their own chains. What we make today we may have to wear tomorrow.

Thank you