

Office of the Disability Services Commissioner (DSC)

Presentation to the La Trobe University Intellectual Disability Policy Roundtable November 2011

Family Engagement Project A Call for Change

OVERVIEW

The Disability Services Commissioner (DSC) calls on the disability sector in Victoria to support the development and implementation of policy and practice aimed at improving relationships between service providers and the families of the people with a disability whom they support.

Based on findings arising from over four years of operation, DSC believes that there needs to be an increased focus within the sector on establishing mutual expectations and agreement between service providers and families in relation to the provision of disability services. As discussed in this paper, DSC believes that doing so will result in increased levels of satisfaction and improved outcomes for people with a disability. This paper has also been informed by a series of 'think tank' consultations held in September and October 2011 with key stakeholders including service providers, family and carer groups, advocates, and academics.

PART ONE – DSC MANDATE AND FUNCTIONS

The *Disability Act* 2006 (the Act) specifies functions and powers of the DSC that require us to:

- Review and identify causes of complaints and to suggest ways of removing and minimising those causes (s 16 (b))
- Consider ways of improving disability services complaint systems (s 16 (h))
- Provide training about the prevention and resolution of complaints relating to disability services (s 16 (o))
- Conduct research into complaints relating to disability services and mechanisms for resolving complaints relating to disability services (s 16 (p))

The Act also provides that in facilitating the resolution of complaints we seek to improve service delivery. We do this through a conciliatory framework, giving voice to stakeholders in the provision of disability services in Victoria.

Information and experiences that inform DSC's practice and knowledge are drawn from all three areas of our operation as follows:

- 1. Sector monitoring and analysis of complaints** - The Act requires all registered disability services in Victoria to report to DSC, through the Annual Complaints Reporting (ACR) process, on all complaints received in each financial year. In 2010/11 there was for the first time a 100% response rate by disability services. Whilst overall complaint trends reported by service providers are similar to data collected by DSC, one in three disability services reported zero complaint activity over the past four years. At DSC we estimate that less than 1% of people in with a disability (and/or their families) make complaints about the services they receive¹.
- 2. Capacity Development** - DSC's Capacity Development (CD) Team, works directly with the disability sector to raise awareness about people's right to complain and provide advice on improving the handling of complaints. In that task the team meets and consults with representatives of agencies, parent associations, service users, their family members, members of the community and advocates. DSC representatives also participate in forums and conferences in the disability sector.

In 2010, the Commissioner and staff at DSC travelled to all states and territories of Australia to speak to agencies that deal with complaints not only in the disability sector but also in health services and human rights. The importance of constructive engagement between families and agencies is not isolated to Victoria or to the disability sector. From our consultations we found that there is a call from many quarters for attention to the issue of the role of families in the provision of care.

- 3. Complaints and Enquiries to DSC** - The Assessment and Conciliation (A&C) Team respond to enquiries and complaints made to DSC. Over 2,300 enquiries and complaints have been received since the office was established in July 2007. The Act provides that any person may make a complaint to the DSC. The jurisdiction of DSC is confined to complaints about the provision of services by a registered disability service in Victoria or about the way a registered disability service has handled a complaint.

¹ *This figure is calculated on our estimate of the client numbers across Victoria. DSC does not have sufficient information to make a precise calculation but the strong assumption is that there is significant under reporting or that stakeholders are not prepared to complain.*

PART TWO – FINDINGS

Complaints data collected by DSC

Commencing operation on 1 July 2007, DSC now has four full years of data from both our own experiences and those reported by service providers to inform our call for change in family and service provider engagement. (Please refer to our annual reports for a more extensive analysis of complaints data than appears here.)

Although the overall numbers of matters dealt with by DSC and reported by service providers have increased each year, the pattern of enquiries and demand reveal some particularly consistent trends in data as outlined below. The data outlined below is from the DSC 2010-2011 annual report and has, on the whole, been consistent through most of the past four years.

Source of enquires and complaints:

	DSC ²	ACR ³
Families	52%	55%
Service Users	23%	26%
Care/Support staff	12%	10%

Types of services that are the subject of complaints

	DSC	ACR
Shared Supported Accommodation	37%	30%
Individual Support Packages ⁴	26%	13%
Day Programs	16%	22%
Case management	13%	8%

Types of disability of service users⁵

	DSC	ACR
Intellectual disability	66%	65%
Physical disability	43%	21%
Autism	30%	13%

² The DSC figures are those enquiries and complaints that are made directly to DSC.

³ The ACR figures are complaints (not including enquiries) made to service providers and reported to DSC as part of the legislative requirement for all registered service to report annually on their complaint activity.

⁴ Enquiries and complaints about Individual Support Packages are increasing at a rate consistently higher than other service types. At least in part, it is likely that this correlates with the increasing number of ISPs now available to people.

⁵ Note – The percentage figures exceed 100% as many service users have multiple disabilities.

Common themes arising in complaints to DSC

The majority of complaints made to DSC have multiple complexities which include disputed interpretation of facts, policies and rights along with a history of poor communication, broken trust, emotional frustration and exhaustion. Where there is escalating conflict we find that all parties in the situation may suffer. Each side attribute negative personal qualities to the other and person-centred planning may stall as decision making is frustrated and energies are directed at the conflict rather than the task of promoting good support for the person who the complaint is intended to assist. In some instances family members and care/support staff have mentioned to DSC that they have sought assistance for stress and anxiety. Where frustrations escalate some families have taken their family member out of a service as a way of resolving the issues.

DSC's experience over the past four years has found that where families and service providers engage in discussions that explore expectations and acknowledge the differences in understanding of roles and responsibilities, disputes can be resolved even where they seem intractable. DSC's resolution rate has increased steadily over this time, with 70 per cent of complaints being fully or substantially resolved in 2010-2011, with a further 12 percent partially resolved.

Key issues observed by DSC that arise specifically in relation to the relationship between families and service providers include:

Fear

Despite the promotion of DSC's message that 'Its OK to Complain' and the increasing numbers of people raising issues with their service provider or DSC, many families and people with a disability still state that they are afraid to voice their concerns to the service providers whom they rely on to provide care and support. They fear retribution, loss of service and loss of relationship with services that are valued. Many believe that making a complaint is to *cross a line in the sand* with the service provider that will change the relationship permanently.

Given the fear that clearly exists amongst people with a disability and families, we urge the sector not to rest on the assumption that low rates of complaints are entirely due to high rates of satisfaction with service provision. Further, and in the context of delivering person centred supports, we urge service providers to consider improved relationships with families as one of a suite of strategies that should be adopted to reduce people's fear of speaking up about their supports.

Recognition of families and natural supports

Few people in society would dispute that family, friends and other natural supports are typically an important part in people's lives. In spite of issues that can sometimes arise, for the vast majority of people it is these relationships that are often the key to our sense of identity, overall wellbeing and general satisfaction with the life we lead.

It is no different for people with a disability. Indeed, it could be argued that for people with a disability, who often experience higher levels of social isolation than is typical in the general community, the involvement of family and other natural supports becomes even more important. As indicated in DSC's complaints data (see Part 2 above), the majority of people who are the subject of complaints to DSC and service providers have an intellectual disability. As a result they may have difficulty speaking out about any concerns they might have about their supports. In this context, the role of families and other natural supports in advocating for the rights and well-being of people becomes critical. Without such support, many people with an intellectual disability would be without anyone other than their service provider to look out for their day to day well-being and rights.

In recognition of these roles that families and natural supports play in people's lives, the Act requires disability service providers to consider, respect and acknowledge the role of families in supporting people with a disability and where possible strengthen and build their capacity [section 5(3)(h)(i)(j) & (k)]. The Quality Framework for Disability Services in Victoria (2007) also requires that disability providers have in place a *Working with Families* policy that guides their approach to working with the families of the people they support⁶.

In practice, DSC has found few examples of service providers having such a policy in place. Whilst there are many good examples of co-operative and respectful relationships between service providers and families, the lack of a documented approach to this area of service provision often results in practice being dependent upon the attitudes and practices of specific individuals within organisations rather than a planned and considered approach by organisations as a whole.

Differing expectations between families and service providers

Many issues brought to DSC arise specifically as a result of differing expectations between service providers and families in relation to anticipated levels of communication and consultation.

As discussed earlier, the lack of a planned approach by service providers to working families can result in inconsistent experiences for families within organisations and variations in practice when staff change. When combined with a lack of conversation and agreement between service providers and families as to their expectations of each other in relation to levels of communication and consultation, these factors can all contribute to an increased incidence of differing expectations and subsequent disputes.

It is our experience that these scenarios are often the basis of matters brought to DSC and, in our opinion, have the potential to detract from the quality of the supports being offered.

⁶ *Industry Standard 8.11.10*

PART THREE – THE CALL FOR A NEW CONVERSATION BETWEEN FAMILIES AND SERVICE PROVIDERS.

Although DSC is calling for changes in aspects of the engagement between families and service providers, we recognise that at a broader level there are many examples of strong engagement between families and service providers in the disability sector. Many agencies have family member participation at Board level, on quality advisory groups and in fund raising. Families have been pioneers in service development in Victoria and many service providers can point to a wonderful record of achievement in including families in their planning and service provision. Many services owe their existence to the work of families.

As previously indicated, where difficulties arise in relationships between families and service providers, they are most commonly caused by differences in expectation about the level of communication and consultation that will occur.

Based on DSC's observations across the capacity development, enquiry and complaints functions, we call for the creation of a clearer set of policy and practice guidelines that not only recognises the importance of family in the lives of people with a disability, but also focusing on the issue of supporting people with a disability within the context of their family and other natural supports.

Whether as part of a broader *Working with Families* policy or as a stand alone document, DSC also calls for an increased emphasis by service providers on taking a lead role in initiating agreements with people's families and other natural supports to achieve mutual and agreed expectations of each other in relation to communication and consultation.

DSC suggests that the conversation between service providers and families should be developed within a person centred framework and consist of four parts as follows:

1. New Conversation – First part: *Translating principles (of the Act) into a service approach for the individual.*

Frequently we find that families and service providers are at odds about what should occur for the person who is being supported, and this in turn is connected to the fundamental understandings about how these principles are translated into practice. A common issue is the aim to promote independence and choice for a person. Families may dispute the basic direction of the service. The aspirational aims of the service provider may look like a risk to the family. These issues may undermine the service delivery and need to be addressed early in the provision of service.

2. New Conversation –Second part: *Clarifying mutual expectations and responsibilities between the service provider and the family.*

From a complaints perspective the conversation and agreement needs to address at least four issues that are frequently the source of dispute and complaint between service providers and families, they are:

1. The provision of information between service providers and families. Each has access to information and each needs access to information. The issue is what is reasonable to expect and what the purpose of the provision of the information is. It is also important to establish the best means of communicating.
2. The respective roles in planning for the person who is being supported.
3. The respective roles in implementing plans and generally supporting the person with a disability.
4. The respective roles in decision making around the support needs and life choices of the person with a disability.

DSC's experience has shown that where families and service providers engage in discussions that explore expectations and acknowledge the differences in understanding of roles and responsibilities, disputes can be resolved even where they seem intractable. We believe that having these conversations during the development of the disability supports to be offered would significantly reduce the likelihood of future disputes and/or provide information that may assist in the resolution of any disputes that do arise.

3. New Conversation- Third part: *'Responding to adverse events and crises.'*

Where the person who is being supported by the service provider is subject to an adverse event or a crisis in care arises, the family needs a different set of arrangement to the normal in terms of provision of information, briefing and support. Some families have spoken to DSC in terms of being 'traumatised' as a consequence of injury to their family member but the trauma is said to be magnified by the actions of service providers where they appear to ignore the family in the response to an adverse event. The purpose of contacting the family about an adverse event also needs to be clear, as to whether it is to provide information or to engage the family in providing support to the person affected.

4. New Conversation – Fourth part: *'Agreeing on what to do when we do not agree'.*

Things can go very wrong when families and service providers have no ground rules and agreed process for communication and behaving in the situation where either becomes dissatisfied even distressed by the behaviour of the other. Dispute resolution systems work best if the parties have designed them before a dispute arises.

PART FOUR- REALISING THE CALL FOR CHANGE

DSC's proposed approach includes five component strategies, which we envisage would be overseen by a Reference Group to guide the approach:

1. Surveying the disability sector to highlight the many initiatives around including families.
2. Policy development that better articulates the roles and responsibilities of families in relation to service provision in the disability sector.
3. Developing a set of criterion for the use of service providers and families to guide their discussions and establish a documented agreement as to expectations and responsibilities.
4. A literature review of research and descriptions of family relationship building with service providers in the disability service area.
5. Consult and explore the numerous related developments in the policy context of guardianship/assisted decision making, circles of support, supportive environments etc.

We believe that the disability service providers and families will make the new conversations and subsequent agreements work best where they can adapt them to their particular service and needs. This in turn can best be progressed through an action research approach and DSC proposes to invite a few service providers to trial the idea of the 'new conversations' with families.

The ideas outlined here are in their formative stage and DSC welcomes comment and debate at the Policy Roundtable.

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