Victorian Disability Services Commissioner – August 2010

Background

The Victorian Disability Services Commissioner commenced on 1 July 2007 under the *Disability Act* 2006 to improve services for people with a disability in Victoria.

This independent statutory office works with people with a disability and disability service providers in Victoria to resolve complaints.

Our complaints resolution process is free, confidential and supportive and we encourage and assist the resolution of complaints in a variety of ways including discussions, conciliation processes, or under certain circumstances through investigations.

At the conclusion of three years of establishment of this office we are able to compare the experiences we have gained in responding to over 1,300 matters to date.

Results increasingly show issues we have dealt with have been resolved informally and many people have reflected the affirmation they have felt and the improved circumstances they experienced as a result of their dealings with us.

There is an obvious benefit in this being the experience of people with a disability and we believe this confirms the value of this dimension of the Victorian *Disability Act* 2006 and subsequent practice approaches we have adopted.

Our key message is '*It's OK to complain!*' We place significant emphasis on education to support cultural change and as such have produced a range of resources that have contributed to improved complaints handling, including a Good Practice Guide.

Victorian Disability service providers readily contribute to our growing body of knowledge by reporting each year on the number and types of complaints they received and how they were resolved. This information is used to identify systemic issues and inform the ongoing development of the disability service system.

There are both themes we can see and conclusions we can draw from service provider's data and our own data that captures our experience of the complaints brought to our office which informs our submission to this Inquiry.

We provide a summary of some of the systemic causes of complaints we have identified for consideration by this inquiry which a new scheme may address in order to achieve better outcomes for people with a disability.

Complaints

Complaints to us can be about any aspect of disability service provision, and therefore includes complaints about adverse events and circumstances experienced by people with a disability and their families. We have evidence of emerging trends that reveal some broader systemic implications that include, but are not limited to, issues relating to accommodation services, the role of families, children's services, aspects of service provision, staffing and workforce issues and out-of-scope matters which reflect our legislative remit.

Enquiries and complaints to the Commissioner are currently made about a range of service types. Shared supported accommodation currently accounts for the greatest share of our in-scope enquiries and complaints, followed by case management, individual support packages, day programs and respite.

People contacting us more often raise multiple issues and concerns, which can be grouped into nine broad categories:

- service provision
- communication
- service access
- service quality
- policy / procedure
- relationships
- legislation / regulations
- privacy / breach of confidentiality, and:
- human resources

The main issues brought to our office over the past three years have mostly related to:

- Service provision
- Communication
- Service access, and:
- Service quality

The **service provision** category includes a range of issues including:

- the individual needs of the service users, including a broad range of issues about access to relevant services, information about government and community service and support options (including legal support, advocacy and other complaints bodies and processes), concerns about the cost of services and concerns about the quality or sufficiency of services relative to the needs of service users.
- concerns about alleged abuse, assaults or neglect of service users, including concerns about the behaviour and actions by staff or other service users, other health and safety issues and the service providers' responsibilities to address identified risks for service users.
- concerns about decision making or choices made by service providers, including in relation to decisions about access to services or activities for service users, changes in the way services are provided (including changing the location of residents of accommodation services) and lack of explanation of reasons for decisions and changes and;
- other issues about service provision including concerns about the quality or suitability of workers, the suitability of planning to assist service users and other general concerns about the sufficiency and quality of service.

The most commonly identified problems with **communication** are currently about a lack of it or unclear information provided to parents or service users (including with regard to changes in services delivered, service planning, decision-making or the cost of services) and providers not responding to communication from a person raising a complaint or not responding in a timely manner.

A number of people raise their concerns with us about a lack of consultation or involvement in decisions to change the way that services are provided to service users. In several cases, communication problems have resulted from deterioration in relationships and a loss of trust between the complainant and service provider.

Issues raised about **access to services** included callers being uncertain about where to access help or how to apply for services, lack of information about available service options (including the range of options available and information about specific support options), an inability to access required services (in some cases due to long waiting periods, failure to meet eligibility criteria or lack of availability) and a reduction in the amount of service provided to some service users.

Service quality issues covered a broad range of concerns about the quality and level of care or support provided to service users (including some instances of neglect), concerns about quality or sufficiency of support workers and issues related to the health or wellbeing of service users (including appropriateness of medication).

Complaints Trends

Shared Supported Accommodation

The highest proportion of enquiries and complaints relate to concerns about shared supported accommodation. This has been consistent over the past three years and currently represents over one third of complaints to us and just under one third to disability service providers across Victoria.

In several matters raised with us in 2009–10, the systemic issues relating to accommodation issues included:

- access to shared supported accommodation
- concerns about competing needs and the ‘compatibility’ of residents
- planning and transition for new residents
- alleged assaults, risks and ‘duty of care’ issues
- quality of support issues in terms of individual needs, choice and community access
- capacity to meet specific needs of residents with autism or mental illness
- physical conditions and facilities
- decisions about relocation of residents

Family related matters

About half of the complaints received by us and by disability service providers are made by parents and other family members of people receiving services.

This has been consistent over the past three years and in this year represented nearly half of the complaints brought to us and to disability service providers across Victoria. Systemic issues relating to the role of families in service provision and decision making were again identified in matters raised with us this year.

Children with a disability

We are approached by service providers concerned about the adequacy of service responses to the needs of children and young people with a disability in the child protection system and in out-of-home care.

General Service provision

Service providers reported to us that over one third of their complaints either related to lack of care or service provided or dissatisfaction with the quality of service. Fewer than half the complaints brought to us this year related to a range of service provision issues.

Workforce issues

Complaints reported by disability service providers this year related to staff behaviour or attitudes, concerns about the match between staff and the person with a disability or concerns about the knowledge or skill of workers. Staffing issues were identified as systemic issues in nearly one third of matters raised with us this year.

Staffing Issues identified in enquiries and complaints to us have included concerns about consistency of staff, the impact of staff turnover on people with a disability, concerns about the competencies and skills of staff. Person-centred practices recognise the importance of the relationships and ‘fit’ between staff and people receiving services. The themes in complaints to us reinforce the importance of building the workforce capacity in the disability sector as a critical component of achieving improved service outcomes for people with a disability.

Out-of-scope issues

We have observed a growing number of enquiries and complaints being made about disability services provided by non-registered providers. These services are outside our jurisdiction (out-of-scope) for us as the Victorian *Disability Act* 2006 defines disability services as those provided by registered disability service providers or by the Secretary of the Department of Human Services. With increased opportunities being created for people to choose their own service provision arrangements through self-directed support funding, it is possible that more people may choose to have services provided by non-registered providers. There is concern that people choosing to access non-registered disability service providers may be disadvantaged through lack of access to the rights, protections and complaint resolution options afforded by the *Disability Act* 2006.

Systemic Issues in Complaints

Underlying systemic issues identified in complaints dealt with in 2009-10, showed in some instances that more than one systemic issue was identified and most commonly related to the following:

- **The role of the family of people with a disability**, including the important role that families play in raising concerns about the provision of services to service users, the dynamic of communication and relationships between families and service providers and the impact that this interaction can have on the extent to which issues arise in service provision:
  - In several complaints, issues involved disagreement between the family and the service provider on the best way to provide services and support to the person with a disability (e.g. in relation to accommodation arrangements, activities, service planning or medication levels).
  - In a few complaints, the wishes of the family about what they considered 'important for' the person with a disability appeared to differ from what the person receiving the service viewed to be 'important to' themselves.
  - In some complaints, families and service providers differed on issues such as the capacity of the person with a disability to make choices and views about his or her support needs.

- **Accommodation issues** including the right to be safe and have quiet enjoyment in an accommodation service. These matters are often related to the support provisions and supervision offered in the accommodation service. Some complaints related to relocation decisions (including decisions to move residents or close services). The planning and transition management for people with a disability, where a new person was moving into a shared supported accommodation service, was a common aspect of several complaints.

- **Unmet needs of people with a disability** in relation to accessing services and resources. In many cases this concerned accommodation issues, including delays in accessing accommodation and the suitability of accommodation or the impact of people living together in services, the match between the person with a disability and the level or type of service offered or concerns about assessment processes and eligibility for services.

- **Staffing issues** including consistency of staff, the impact of staff turnover on people with a disability, concerns about the appropriateness and skills of staff, reliability and quality of in-home support, and alleged assaults or mistreatment by staff.

- **Lack of person-centred planning or approaches** including services not matching the person's requirements (in some cases due to lack of flexibility in the way that services are delivered), concerns about the management of changes to the way that service is provided (particularly with regard to closure of accommodation services), perceived lack of consultation or consideration of the views of complainants and general insufficient or inappropriate planning.

- **Service provider's approach to complaints handling** including lack of a clear complaints process and inadequate management or follow up on complaints.

- **Policy or legislative issues** including gaps in available services and issues about the way those policies are implemented.

Case Stories

Grace

Grace made a complaint to DSC when she was informed that her child's case worker was being changed. Grace is the mother of a young child who is deaf and has autism. The complaint was about her fear that the quality of service they had been experiencing was about to change. Grace felt they had not been consulted and that the service could not see the real impact this change would have on her family. In response to the complaint the service provider offered to meet with Grace and explain their decision-making process. They also listened to her concerns and her feedback about what had been working well. During the meeting the service provider apologised for the distress caused to the family and agreed that the family should have the opportunity to say goodbye to the worker who had been so important to the family. Together they agreed on a transition plan, the qualities and skills needed in a worker to meet this families needs and a timeframe for the change. The service wrote to Grace and told her that they would use her experience as a way to review relevant policies and procedures. Grace told DSC that this step gave her hope that they can work together and learn from these issues.

Carol

Carol contacted DSC to discuss the implications of an event which had occurred while her daughter was on a camp. The camp was promoted as a getaway for women with a disability. Carol's daughter had been looking forward to the camp's activities and a break away from her group home. An incident occurred while on camp and Carol's daughter was sent home. Carol raised concerns about a lack of supervision for her daughter and a change in the program which meant that it was not a women's only camp. DSC checked the register of disability providers and informed Carol that the organisation was not a registered disability service provider. This meant that DSC was not able to deal with the complaint. DSC was able to inform Carol that the organisation was a registered travel agent and therefore her complaint could be taken to Consumer Affairs and was provided with information about how to do this.

Simon

Simon made a complaint to DSC about his daughter Sophia's day service provider not following through on concerns about a therapy program. When Simon tried to complain he felt that the service provider did not address his concerns. In assessing the complaint, officers from DSC discovered that while the original complaint issues had been acknowledged and explanations provided, there was a high level of distrust between Simon and the service provider. This distrust had escalated to the point where there was very little communication possible about services for Sophia. DSC officers worked with Simon and the day service provider to understand how the conflict had escalated and why the original complaint was not considered further. DSC provided advice about what both the service provider and Simon could do to improve their ongoing relationship and to work in partnership to achieve positive outcomes for Sophia.

John

John submitted a complaint about a service provider regarding his adult children Tim and Sarah who lived at home with him and had high support needs. The complaint was about how the service provider was managing the large number of support workers and shifts required to care for Tim and Sarah. John said that carers would not turn up or were not properly trained. He said there were several gaps in the roster and these were often filled by John. This was impacting on his health and he did not want to have to fill any shifts that the service provider was unable to fill. An assessment conference was arranged to work through the issues raised by John. At the conference, the provider acknowledged the time and effort John put into looking after Tim and Sarah. It was agreed that a six-week roster would be drawn up and that the service provider would have sole responsibility for the roster with input from the family. John would not be filling in for vacant shifts that appeared on the roster. On closure of the complaint, while all issues were not resolved, John and the service provider agreed to working together to resolve the remaining issues. They agreed to meet regularly, both be responsible for recruiting new staff and agreed on how they would communicate when problems arose.

Susan

Susan called with concerns about an organised holiday that her brother Bill went on with other people with disabilities and a number of carers. While on the holiday, Bill was given a large sum of money by the venue staff while at a casino to spend on gambling. Upon his return home, the casino manager contacted Bill's sister as his administrator and requested payment of the monies lent to her brother for use in the casino. Susan wanted to complain about the duty of care of the casino staff, and how her brother was given money to gamble without her knowledge. She was also having difficulty contacting the venue manager and finding the right person to resolve the issue with. As the complaint was out of scope for the Disability Services Commissioner, DSC staff assisted Susan by finding information about the company's complaints process and also advising her of the option of making a complaint to Consumer Affairs. Susan was extremely satisfied with the assistance she received from DSC and expressed her gratitude in a follow up email.

Christine

Christine, a 40-year old with a physical and sensory disability made a complaint about a new resident at her group home. She raised a number of issues about the new resident's behaviour, ranging from annoying or disruptive behaviour to actions which could be dangerous for some residents. Christine made a request that the new resident be shifted and felt that her concerns were not taken seriously by her service provider.

The DSC officer met with Christine to discuss her complaint prior to arranging a joint meeting with the house supervisor and area manager of the service. At this meeting a clear plan was developed to address what was not working well for both the new resident and the five long-term residents. This plan included initiatives and activities to help the new resident, along with house meetings for all residents to foster positive communication about house issues. It was agreed that Christine would be involved in the planning of the agendas for the house meetings, and Christine was pleased with the response by the service provider to her complaint.

During this process it became apparent that Christine had been affected by the changes at the house more than other residents due to changes in her own lifestyle. The DSC officer facilitated a review of the individual planning for Christine, who had been without activities or a day program for some months due to health issues. Following a review of her medical and transport requirements Christine was able to resume her day program as well as access more activities outside the house. Her quality of life improved as a consequence of actions taken in response to her complaint.

George

George is a direct care worker who made a complaint about practices in the group home where he worked. George said that he witnessed many examples of poor practice in the care of people with disabilities and outlined specific examples in his complaint. George expressed frustration and a belief that the culture of the service was old fashioned and did not reflect person-centred approaches to supporting people. George wanted to remain anonymous. He believed that he would be disadvantaged if his name was known to the service provider. DSC approached the complaint by conducting a systematic assessment of each of the alleged practices raised in relation to the residents. Some allegations about practices could not be substantiated. Other issues were acknowledged and explained by the service provider. The DSC officer gave George a full account of the assessment steps and the actions that the service provider had agreed to take in relation to the support needs of the residents. George accepted the assessment by DSC that the provider had responded to the key concerns raised in the complaint and were taking steps to address them. George also felt satisfied that an independent body had looked at the issues and was prepared to engage him in discussion about the concerns he had raised on behalf of the residents of the service.

Mike

Mike and Jen complained about a service providing day programs to their daughter through an individualised support plan. One aspect of the complaint was that the service had 'deteriorated' in the past 12 months. The family believed support workers were not doing their job, that they seemed to be less inclined to stick to the planned programs and they did not encourage service users to participate in programs. When staff and management explained that the policy had changed very deliberately to give service users more choice and 'mix the program up' to provide some variety, Mike and Jen were upset at the lack of consultation. They believed the explanation confirmed their view that staff just did not want to 'go the extra mile' for the service users. Communication between the agency and family broke down and disputes escalated. This drew in more families and raised more issues regarding policy and practice. The complaint process provided a 'circuit breaker' and the disputes were able to be contained for a month as parties agreed to discussions about the expectations of the family and the directions of the provider. The complaint process enabled the discussion to focus on service user's responses to the changes and person-centred approaches to understand what was working or not working for them.

Malcolm

Malcolm is a 25-year old man with an intellectual disability. He was not happy with his individual support plan, as he wanted to go swimming every week instead of once a fortnight as set out in his plan. Malcolm's advocate Sarah submitted a complaint on his behalf on the basis that Malcolm's plan was not up to date as it had not been reviewed for three years and did not reflect his current interests. The service provider's response to the complaint indicated that they were not aware that Malcolm wanted to go swimming more often and they offered him individual support for two hours every week so he could go swimming. The service provider acknowledged they had not reviewed Malcolm's individual support plan and provided an apology. They then made arrangements to support Malcolm to follow his interests and improve his quality of life.

Helen and Gerard

Helen and Gerard made a complaint so they could find a better way to be actively involved in the decision making around their son Bill's life. The family talked about their emotional decision to request shared supported accommodation for Bill. After a long wait Bill was successful in obtaining accommodation and appeared to be settled in his new home. The family believed the support workers were committed and competent. After Bill moved into the house, however, the family became increasingly concerned about the policies of the service provider. There were several aspects of policy and practice that they felt had negative impacts on Bill and they wanted the provider to make some changes. They felt the service provider was allowing Bill to have too much choice, which in their view was leading to him placing himself at unacceptable risk. Helen and Gerard felt dismissed after raising these concerns with the service, and made a complaint to DSC. In the course of assisting the parties to resolve the complaint the assessment officer arranged an assessment conference. The family and two managers from the service were able to sort through most issues and reach an agreement about how communication could work better in the future. The meeting did not give the family all they wanted but they commented that they had never met the managers before and that it would have saved much heartache had they understood some of the thinking and approaches of the service provider from the start.

People with a disability, their families and carers have told us:

'*People don't know what is wrong unless I tell them' Person using disability services.*

'I can have a friend help me when I want to complain' Person using disability services.

'It is good to tell my worker when she does things that I like' Person using disability services.

'It is good to know to always state the outcome you are seeking when making a complaint' Parent.

'I now know that I should complain when something goes wrong as it gives the service an opportunity to fix the issue. If I say nothing it may happen to someone else as well' Parent.

'Sometimes I feel my provider does not listen. So it is good I can call your office' Parent.

'….the information session helped to highlight the issue that many parents or carers are scared to complain in case they lose services' Parent.

'……important to know that each organisation is required to have a complaints system which should be used first before referring to the Commissioner' Parent

Discussion and Conclusions

Inclusion

We believe any new scheme should be inclusive of children and adults with a disability, and not confined to those with severe or profound disabilities. The definition of disability found in the Victorian *Disability Act* 2006 would be a useful starting point for developing eligibility criteria for a new scheme. This definition attempts to identify the impact of a person's disability in the broad areas of '*self-care, self-management, mobility or communication'* and the need for ongoing or episodic support. Whilst the definition under the Victorian *Disability Act* 2006 requires a disability to be assessed as permanent or likely to be permanent, a new insurance based scheme has the potential of being more inclusive and adaptable to cater for disabilities assessed as temporary.

The inclusion of autism as a specific disability within the definition is recommended. Under the Victorian *Disability Act* 2006 autism has been considered a neurological impairment in order for people to be able to access disability services. In 2009-10 27 per cent of enquiries and complaints to the Office of the Disability Services Commissioner related to services for children, young people or adults with autism.

Supports and Needs

Our experience provides some insight into the areas in need of additional support. We suggest that any assessment of the relative and unmet needs for support needs should be informed by individualised assessment of support needs rather than by types of disabilities or population groups. Such assessments should be informed by a person centred approach which starts with what is important to and for the person, their individual needs and aspirations and their family and social context. A new scheme should encourage the full participation by people with disability and their families/carers in the community, and be informed by concepts such as circles of support.

We consider that a new scheme that entitles a person to supports based on an individualised assessment of support needs would reduce the expressed concerns about unfairness in current disability service provision.

Decision making

To ensure people with disabilities or their carers have more power to make their own decisions and can appeal decisions by others, we believe the principles which should inform a new scheme should be a rights-based legislative framework, similar to that of the Victorian *Disability Act* 2006. This legislation recognises the rights of people with a disability to exercise the maximum control over their life and decision making and models of individualised and self directed funding of support arrangements should flow from these principles.

Rights and Protections

Any new system should as a minimum include the types of protections and safeguards set out in the Victorian *Disability Act* 2006, and the mechanisms for ensuring accountability and quality of services. We strongly support a scheme that includes an independent complaints body and processes for independent review of decisions as key a component for upholding people's rights and ensuring accountability and quality of services. We support any scheme that promotes the exercise of control and choice inherent in self-directed support models whilst maintaining options for ensuring individual rights and protections are maintained and strengthened.

Services

Any increase in services needs to balance the availability of core services for people to access and the creation of individualised services to meet a person's needs, wishes and circumstances. It is important that sufficient 'core services' are available whilst at the same time not tying resources up so as to minimize the degree to which people can determine the supports they want and need based on their own vision for their life. The complaints made to our office suggest that the most common unmet needs in service provision are supported accommodation options and choice of models, followed by case management, individual support packages, day program options and respite.

Service Delivery

Services can be improved if they are informed by proactive person centred planning and approaches, up to date assessments and forecast planning for changes in people's support needs. Improved outcomes over people's lifetimes can be achieved through person centred approaches which pay attention to what is working and not working for the person and tailoring supports to their needs and aspirations. It needs to be recognised that disability services are most often provided in a context of an ongoing relationship between the person and his/her service provider and support workers. The quality of the service is therefore dependent to a large degree on having a strong and diverse workforce, with the capacity to match support workers to people's individual needs and preferences, and incentives for workers to continue in ongoing roles.