

National Disability Insurance Scheme DRAFT REPORT – Submission

Disability Care and Support

SUBMISSION - 30 APRIL 2011

Attention: Disability Care and Support Inquiry

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1. 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, their families and disability service providers in Victoria to resolve complaints, provide education and training on complaints processes and review systemic causes of complaints through analysis of annual complaints reporting data from disability service providers.

This combination of functions, together with the educative approaches adopted by the office, has produced improved outcomes for individuals receiving disability services, along with significant quality improvements in the way in which disability services are provided.

The experience and successes of this uniquely established statutory authority in providing an accessible and specialist complaint mechanism for people with a disability has particular and significant relevance for recommendations in Chapter 7.

Please refer to the Disability Services Commissioner's submission provided in August 2010 for further background information on the role and experience of this office.

2. Introduction

The Victorian Disability Services Commissioner welcomes the Australian Government's initiative to address the identified issues and gaps in the disability service system, and the need to provide greater certainty and control to people with a disability and their families in relation to disability supports.

There are many encouraging features in the proposed scheme which is designed to address existing deficiencies, and enable a greater number of people with a disability to access the supports they need with a sense of entitlement and control over decision making.

From the experience of the office of Disability Services Commissioner (DSC), we believe we are uniquely placed to identify and provide a number of important learnings in relation to the appeal and complaint mechanisms that would benefit from deeper consideration, based on the demonstrated strengths of the approaches developed by this office and supported by the Victorian disability legislation.

3. Feedback on proposed appeal and complaint mechanisms

Appeal and complaint mechanisms based on insurance schemes rather than specialist disability statutory models.

We note that the proposed appeal and complaint mechanisms are based primarily on the complaints models for existing insurance and accident schemes. We respectfully put forward that these models have not been designed to meet the specific needs of children and adults with a disability, in particular people with lifelong disabilities such as intellectual disability and autism, and people with multiple and complex needs.

Over half of the complaints dealt with by our office are made in relation to people with multiple disabilities and support needs, with the majority (60 percent) having an intellectual disability and over a quarter experiencing autism (Disability Services Commissioner Annual report 2009-10).

Based on our experience we have formed the view that by comparison to a statutory body such as the Victorian Disability Services Commissioner, appeal and complaint mechanisms developed for insurance and accident schemes may have limitations in addressing the specific needs and challenges of ensuring accessible and effective appeal and resolution processes for this population group. An effective complaints model would, by design, be one that can effectively address the specific nature of issues likely to arise in the areas of support needs assessment and disability service provision as well as perform other activities such as mediation, facilitation or dispute resolution for people with the range of disabilities that will be targeted by the NDIS.

In addition to actual complaints dealt with by our office, a significant portion (76 per cent in 2009-10) of our contact with people with a disability and their families is responding to enquiries through which they seek our advice on a range of matters relevant to concerns they have about their disability supports. Anecdotal feedback suggests that it is the independent nature of our office that is a significant factor in

people being confident about contacting us for advice, which often leads to them attempting to resolve their concerns directly with their service provider.

The proposed appeal and complaint mechanisms do not offer full statutory independence. Our experience is that this is critical to successfully engaging people with a disability and providing an accessible and effective complaints resolution services. The proposed 'programmatic separation' of a statutory officer working within a NDIA does not offer the type of external, independent complaints and appeal mechanism that people with a disability, their families and service providers have indicated (at least in Victoria) is required to have confidence in the efficacy and fairness of the proposed scheme.

As put forward in our earlier submission, we strongly support a scheme that includes an independent complaints body and processes for independent review of decisions as key components for upholding people's rights and ensuring accountability and quality of services. An independent statutory authority is suggested to fulfill this function and in particular serve to address those complaints and matters where it is not appropriate that the function be performed by the NDIA or an 'independent program' within.

Central to the establishment of any complaints body is the need to address the potential for real or perceived conflicts of interest. This is particularly so for the complaints mechanism proposed as part of this scheme. It is therefore critical that the model adopted instills confidence amongst all stakeholders of having the levels of impartiality and integrity necessary to objectively examine a range of actions or decisions of public officials and non government services. This would be achieved through the creation of a separate independent Statutory Authority that is governed by an individual appointment.

A unique opportunity exists to ensure that the first national disability insurance scheme includes appeal and complaint mechanisms that reflect the overall aim of improved equity, efficacy and quality of disability service provision and a person centred approach to service delivery. In order for this opportunity to be realised, we put forward the importance of considering the benefits of the model and approaches adopted by this office, and the need for the complaint and appeal mechanisms to address the particular nature of issues and disputes that are likely to arise in relation to assessments, decision making and service provision under the proposed scheme.

Our experience of working with people with a disability and their families who seek reviews of decisions or remedies of complaints about disability service provision indicates that the following factors as being critical to successful engagement and complaint outcomes:

Educative and outreach approaches and resources which address people's reluctance and fear to make a complaint.

Consistent and accessible messages about the right to complain and the way in which complaints can lead to improved services.

The independence of the Commissioner and his commitment to promoting the rights of people with a disability and quality improvement of services.

A range of resources, formats and approaches which promote access, understanding and participation for people with a disability, including pictorial and easy English formats for people with an intellectual disability.

Articulated objectives, values and principles which underpin the approaches taken to complaint resolution.

Flexible assessment and complaint resolution processes which are adapted to the particular needs of people with a disability and circumstances of the complaint.

Particular skills are required to work with people with a disability, their families and service providers where there are disputed claims as to whose interests are serviced in the complaint.

Recognition of the ongoing relationship that is likely to exist between the person with a disability, their family and the service provider.

Reference to rights, principles, standards and safeguards set out in legislation.

A range of legislated options and powers for dealing with complaints, including assessment, informal resolution, conciliation and investigation.

A proactive and significant emphasis on education to support cultural change and service improvements by disability service providers, including a range of resources that have contributed to improved complaints handling, including a Good Practice Guide.

Evidence that systemic issues are identified and are used to inform developments and improvements in disability services.

Overview of the benefits of the Victorian Disability Services Commissioner (DSC) model.

Since the establishment of this office on 1 July 2007, we have responded to increasing numbers of enquiries and complaints (over 1800 matters to date). These numbers have increased by approximately 35 per cent each year, reflecting the success of strategies to promote the awareness and accessibility of the office and practice approaches adopted. In particular, the numbers of people with a disability raising issues on their own behalf steadily increased to the current figure of almost one quarter of all enquiries and complaints. It is worth noting that, whilst the rate of complaints appears low, from the response we have seen to date we believe that the demand for a complaint service is likely to be far greater than the numbers DSC has dealt with to date.

The practices and approaches developed by the office has enabled us to increase the number of complaints informally resolved from 22 per cent in the first year to 60 per cent in 2009-10, along with significant positive resolutions and service improvements for the majority of formally considered complaints.

Through feedback and evaluations, 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 the practice approaches we have adopted. We have received positive feedback from people who have raised a complaint and service providers about our method of responding to complaints and focus on finding ways to reach mutual agreement about how best to resolve complaints.

Our capacity development and education activities have been critical to the success of the work of office and in promoting cultural change and positive complaint handling. We promote the use of our Good Practice Guide for effective 'person centred' complaint management, and the message 'It's OK to complain!' throughout the Victorian disability sector and we have seen this adopted in other jurisdictions in Australia. Our education work has been enhanced through the development of additional resources including DVDs, CDs and culture questionnaires. We have been encouraged by service provider feedback that these tools provide useful resources which contribute to improvements in complaints handling.

Further to this, disability service providers are required by the Victorian Disability Act 2006 to report each year on the number and types of complaints they receive and how they were resolved. Our approach is to emphasise the value and significance of Section 105 of the Act as an opportunity to contribute to the body of knowledge available to inform the ongoing development of the disability service system, as distinct from emphasising annual complaint reporting compliance obligations. We continue to see increasing levels of contribution with 81 per cent compliance in the 2009-10 year. The increasing levels of both compliance and contributions to the reporting process suggests that we are beginning to see a genuine shift in the attitude to, and management of, complaints by Victorian service providers. It is our opinion that this will ultimately lead to improved services and better outcomes for people with a disability and their families.

This annual reporting requirement of service providers is unique to Victorian legislation. It provides evidence of service user's experiences and a reliable source of data that is used to understand what has or has not worked well for services and service users. The data supports research and education, assists to identify ways to improve complaint handling, share examples of good practice with the disability services sector, inform submissions to government annual reports to Parliament, information for service providers and contribute to service improvements in the disability sector.

Through analysing data from complaints made to DSC, along with the annual complaint reporting data from disability service providers, we have identified a number of emerging trends and systemic issues and ways in which these might be addressed to achieve better service outcomes for people with a disability.

3.3 Case examples of the benefits of DSC's specialist approaches.

Note: These case examples have been de-identified and some details changed to assist in the de-identification process. The issues and outcomes however accurately reflect the work of DSC.

Preamble

The approaches adopted have been informed by the following objectives articulated for DSC complaint resolution processes:

The rights of people with a disability are upheld and promoted in the complaint process, particularly the right to quality services and to complain: that people feel heard and respected.

The process is 'person centred', with a focus on what is important to and for the person with the disability.

The process focuses on ways of improving service outcomes for the person with a disability.

That the process respects the ongoing relationship between the person with a disability, their family and the service provider: emphasis on earliest possible resolution and creating a better foundation for resolving issues together in the future.

That service providers are assisted to identify opportunities for service improvement through the resolution processes for individual complaints.

One of the key features of disability service provision is that services are most often provided in the context of an ongoing relationship between the person with a disability, their family and the service provider. Even where a person has a choice of moving service providers, as envisaged in the proposed new scheme, experience with similar funding models in Victoria suggests that there are many reasons why a person would prefer not to change providers or may not believe this is a viable option. Changing providers can involve disruptions, lack of continuity of care, uncertainty and loss of relationships. People can be dissatisfied with aspects of the service or an adverse event, but prefer that these aspects be addressed rather than the upheaval of changing a provider. For people living in supported accommodation, changing a service provider can mean changing their whole living situation, leaving their home and friends which is not an easy or realistic option in many circumstances.

DSC's approach to complaint resolution has been informed by the knowledge and experience that it is often necessary to address many intangible issues such as the mutual expectations, confidence and trust between service providers, clients and families, in order to improve disability service provision and the likelihood of better outcomes for the clients of these services. While many complaints are resolved directly by service providers, there are those where the involvement of an independent body with expertise of operating within this context, using a uniquely designed, innovative and tested complaints model, may be required to provide the opportunity to take a different perspective and assist to implement clear processes that are fair and inclusive.

DSC's approach seeks to build understanding between conflicted parties, and the key to this is ensuring processes are designed that to work for the parties to the complaint. It is a conciliatory or alternative dispute resolution approach rather than a 'claim-settlement' approach. Our experience is that a 'claim-settlement' approach is unlikely to resolve the types of issues that are at the centre of most complaints about disability service provision.

Case Example 1 - Jill asks "Why don't they listen?"

The complaint received from Jill was that she believed the service provider had overlooked her request to be moved to another location. Jill stated that she was receiving accommodation and support services from the service provider and that she

had wanted a move to a particular unit (also run by the service provider) in another area. Jill first asked about the move six years ago. When Jill realised that another person had been moved into the unit she wanted, Jill asked that a swap be arranged between the person who had been given the accommodation and someone in a unit nearby. Jill was at a loss to understand how she was not considered for the unit.

DSC findings:

Jill is a 48 year woman with severe physical and communication disabilities. She does not have a cognitive impairment and is able to make decisions for herself.

Jill has been 'in the care' of the service provider since she was a young person and has no family.

Over the past few years Jill has spent more than a year in hospital and rehabilitation for treatment of her declining physical condition. She is increasingly dependent on support and assistance for personal care.

Six years ago Jill spoke to her care staff about her desire to move to another location. She knew the service provider had units in the area and she was keen to be in the area. Jill claimed that she raised this issue on many occasions, at least monthly over the past six years. She understood that she was on a list waiting for the move.

While Jill was in rehabilitation recently she discovered that a unit became available and that another person was allocated the unit. Jill heard about this "on the grapevine", she was extremely disappointed and made a complaint to the service provider.

The service provider stated that there was no record of Jill wanting a move and that she had never been considered for any move. The service provider wrote a letter of apology but this did not address Jill's concerns and so she made a complaint to DSC. The service provider stated to DSC that each year they routinely invite all clients to have a plan for their future and that Jill never responded positively to the invitation. The service provider stated that they valued the client's right to choice and Jill had exercised her right to refuse a plan. The service provider added that Jill had a substantial care/support plan about her day to day care needs and that was working very well. Jill was a long term and a valued client. The service provider felt that there was little that could be done.

DSC designed a process for speaking to each party then bringing the parties together to assist communication. As an independent body DSC was able to invite Jill and the service provider to share their respective views and to facilitate how Jill could be placed on a waiting list. In the course of the process DSC encouraged Jill to articulate what was important to her. The parties made several agreements about how Jill could access a unit and she made plans about travel and social activities which were supported by the service provider. Jill however resolved that she wanted to be less dependent on the formal processes of the service provider. She learned about options and she set her course to move to be independent, to have public housing and to access an Individual Support Package.

Case Example 2 - George and Cecilia dispute the call about how the Individual Support Package (ISP) can be used.

The complaint was made by George and his daughter Cecilia. They made the complaint on behalf of Bill (George's son and Cecilia's brother). The complainants

stated that they could not make sense of the way the service provider interpreted the guidelines for the spending of funds through the ISP. They asserted that “the goal posts keep changing” and that the service provider ought to allow the family’s to decide how Bill could best be helped through the ISP.

DSC findings

Bill is 29 years old. He has severe autism and a mild intellect disability.

Until a year ago Bill had lived on his family’s property, a farm in the western district of Victoria.

Bill’s mother dies 20 years ago and George has cared for Bill.

The family state that no school or other service can deal with Bill. He is 190 centimetres tall and weighs around 110 kilos. He has little tolerance for change and is happiest helping on the farm in close partnership with his father.

George suffered a stroke a year ago and Bill was placed in respite accommodation.

Bill demonstrated behaviours of concern. He harmed himself and destroyed property.

On several occasions he harmed care staff although it is argued that he did this without intention. The fact is that several care staff refused to work with Bill and he was transferred to an institution. The estimated cost for caring for Bill over a ten month period was around \$200,000.00

When George returned to his farm he needed Cecilia to move in to assist him. The family was provided an ISP of \$36,000.00 and Bill returned home.

The ISP has not been accessed in full due to ongoing dispute between the family and the service provider. The disputes are around the interpretation of the ISP guidelines and the service provider’s decision that the family is seeking to use part of the ISP to assist Cecilia rather than Bill. The family argue that the support to Cecilia allows her to assist George and Bill. One particular point of dispute is a request to spend funds on petrol and to assist Cecilia with some support for her children. The family state that the amount in dispute is less than \$7,000.00 that Bill was costing the State much more and that greater flexibility should be used in the interpretation of the guidelines. Ongoing disputes generated a tension between the parties and each attributed personality factors to the other as the reason why funds were not being spent.

The involvement of DSC as an independent body enabled an objective re-examination of the guidelines and identified ways in which the service provider could exercise discretion in the interpretation of these guidelines. In the context of an over heated relationship between the complainant and the service provider, DSC was accepted as a moderating influence and was able to facilitate the parties return to a workable relationship through agreements as to how the communication should be channelled and how future disputes could better be managed.

Case example 3 - Residents in shared supported accommodation complain about being told they have to move to another house in another community.

The complaint was made by Gordon, Peg, Paul, John and Julie, who are in a shared supported accommodation service in the inner city of Melbourne. They received a letter from the service provider advising that they were to move out of their accommodation in the next three months as it was due to be replaced and that a new house could not be built on the site. The residents understood that they may be homeless or ‘forced’ to move far from their community.

DSC findings:

- The five residents, their families and care staff were shocked with the news that they were required to move. The news was traumatic for some.
- The process was part of the state-wide systemic refurbishment and replacement of housing stock.
- The communication strategy appeared to be designed to give little room for questioning the decision or to prepare for the move.
- There were no person-centred plans in place and the move was, in our evaluation, driven by fabric requirements and the machinery of financing and building programs rather than the needs of the individuals served.
- The attempts to resolve the complaint hit a wall of policy and procedural confusion as to the decision making and the respective powers of the service provider to interrupt the machinery of audit and fabric replacement as much of the process was seemingly driven outside the realm of the service provider.
- Advocacy services became involved and the matter was potentially the subject of a media campaign.

DSC worked with the advocacy service, the residents, families and care staff as well as the service provider to consider the problems and the decision making process. Through strong cooperation on part of all parties the audit was reviewed and the decision was made to rebuild on the site. The resolution was healing and restored the confidence between service provider and clients.

Further to dealing with the original complaint, DSC also provided formal advice to and liaised with the service provider thus enabling them to negotiate the barriers to influence the process of the rebuilding program. This resulted in policy changes and improvements to future approaches to proposed relocations, including changes to the methodology of purchasing potential sites for new buildings.

Case example 4 – Conflict and Care

Peta complained on behalf of her son John who resides in a shared supported accommodation service. She stated that the care staff are “hopelessly incompetent, lazy and nasty”. She was prompted to complain when an error was detected in the administration of John’s medication regime.

DSC findings:

Peta stated that she has had issues with the service provider for many years. They just cannot get it right. She stated that she had caused four house supervisors to move out through ensuring they are “accountable and made to perform”. She says she has “zero tolerance for fools”.

The service provider asserted that John is well cared for and his wellbeing is closely monitored. By any criteria, John is doing well. The service provider claimed that Peta is the problem. She is at the house for hours and spends her time overseeing the care staff. She throws meals into the bin if she thinks John should not eat the food. The thing is that much of the food John chooses is not acceptable to Peta. There is confusion about medication as Peta takes John to the doctor and often does not communicate the outcome to care staff.

The service provider expresses a loss as to how to deal with the ongoing conflict with Peta.

DSC can assist in such situations where parties to a complaint appear to have locked themselves into a pattern of expending much energy and time in conflict. The independence of DSC can be a circuit breaker and bring parties to the table to discuss the dynamic and the reasonableness of the respective behaviours. The success of such approaches is also dependent on having officers who are highly skilled in assessment and the application of conflict resolution methodologies such as mediation and conflict coaching. In the context of many years of dispute and tension, the parties agreed on better communication around John's visits to medical practitioners and there were changes to the frequency and duration of visits to the house by Peta. The parties also agreed on a way to discuss disputes if they were to arise in the future.

4. Related areas warranting further consideration

Assessing eligibility and care and support needs- Chapters 3 & 5

From our experience in dealing with complaints about assessments and disputes about the nature and level of support needs, the recommendations regarding eligibility criteria for the proposed scheme (Draft recommendation 3.2) are open to interpretation and definitional disputes. Assessments as to whether a person has 'significant difficulties' in relation to mobility, self-care and/or communication or would derive 'large identifiable benefits from support' will be open to interpretation and carry the risk of excluding people currently being supported through the disability service system. Similarly the proposed reliance on assessment tools to determine an individual's 'reasonable and necessary care and support needs' (Draft recommendation 5.1) is likely to give rise to disputes over interpretation of this criteria and the outcomes being dependent on the skills of the assessor, the circumstances of the assessment, the sources used and the way in which conflicting views and evidence are treated. Whilst we recognise many positive inclusions in the proposed assessment process such as the recommendation that it should be 'person-centred and forward looking and consider the supports that allow a person to achieve their potential in social and economic potential' (Draft recommendation 5.2), the required judgments as to 'reasonableness' of need will leave the decision making open to challenges regarding equity and fairness.

In light of these issues, it is critical that further consideration be given to the processes for assessing eligibility and care and support needs, and that applicants to the scheme have access to an independent review and appeals mechanism.

Accountability and quality frameworks- Chapter 8

One of the strengths of the approaches adopted by our practice has been to promote cultural change in people's and organisations' responses to complaints to be regarded as integral to providing a quality service. Disability service providers have been encouraged to recognise complaints as people's opportunity to speak up about issues experienced, and to see complaints as an opportunity to improve the quality and outcomes of service provision. The annual complaints reporting requirement of service providers has also been promoted to contribute to important data on service

user's experiences and a body of knowledge to inform best practice in complaint handling and quality improvements of the disability service system. In contrast the report refers to complaints only in relation to compliance and monitoring of standards and as possible indicators of poor performance by providers. Based on our experience, we suggest that further consideration is given to promoting the importance of recognising complaints and complaint mechanisms as an integral part of quality assurance and improvement processes.

5. Summary of issues and recommendations

In summary, our experience and growing body of evidence suggests to us that that a number of aspects of the proposed scheme warrant further consideration and revision in order to achieve the desired outcome of rights based, person-centred, fair and equitable scheme and ensure accountability and quality of services. In particular, for the proposed scheme to ensure that people with a disability and their families have genuine input into their supports, it is critical that there is a strong and independent complaints mechanism that supports the development of a culture where people are confident to express their views and are listened to accordingly.

In conclusion, we recommend that consideration be given to:

The need for an independent complaints mechanism, with proven approaches for promoting accessible and effective complaints resolution and improved service outcomes for people with a disability.

The need for an independent review and appeals mechanism.

Further review of the proposed assessment criteria and processes for determining eligibility and care and support needs in order to address the likelihood of definitional disputes and risks of exclusion of people in need of disability supports.

The critical role of education and capacity development activities in promoting the right of people to complain and building the capacity of disability service providers to respond to complaints as an integral part of providing a quality services.

The benefits of an annual complaints reporting requirement for service providers which can contribute to the body of knowledge available to inform best practice in complaint handling and quality improvements of the disability service system.

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