

# **A Response Paper to Victoria's Disability Services Commissioner: Learning from Complaints - Occasional Paper No. 2 – Families and Service Providers Working Together**

**Response Title: The Danger of Telling  
Families that More Principles and  
More Strategies are the Solution**

**Responders: Margaret Ryan and Max Jackson**

March 2014

## About this response

1. This paper is written as a response to the *Learning from Complaints: Occasional Paper No. 2, Families and service providers working together*, published by Victoria's Disability Services Commissioner in January 2014, with feedback invited. <http://www.odsc.vic.gov.au/occasional-papers>
2. While the authors of this response acknowledge the availability of a Feedback form for responses, they have instead elected to respond via this paper.
3. The response is structured in such a way that while it addresses both Parts 1 and 2 of the Occasional Paper the response also makes comment on what the authors define as platform issues, as well as providing a critical comment section. A Summary Statement is also provided and there is a Concluding Comment.
4. In terms of the platform issues these address the following matters:
  - (i) Where are the families?
  - (ii) The concept of the learning cycle and roles and responsibilities
  - (iii) Application of the law
  - (iv) The language of disability
  - (v) The matter of policy principles
  - (vi) The process of engagement
  - (vii) Facts and figures
5. While the authors provide authority to the Disability Services Commissioner (DSC) for the public release of this response, they also reserve their right to make it publicly available.
6. The authors query as to what action and feedback, if any, the Disability Services Commissioner will provide in relation to the responses to the Occasional Paper?

### **Margaret Ryan**

Email: margaret@jacksonryan.com.au  
Contact Number: 0412 409 610

### **Max Jackson**

Email: max@jacksonryan.com.au  
Contact Number: 0413 040 654



## Summary Statement

### The 'More' approach - An art form

The propensity in the disability sector to applaud any activity or publication that purports to enhance progress towards enlightenment has become an expected, and indeed an almost demanded, response. This is particularly so when the activities or publications come from an august body such as the Office of the Disability Services Commissioner or are founded on the work of 'expert' committees.

It has long become a practised art form in the disability sector by those responsible for service monitoring, service funding and the protection of rights, principles, and standards to take the 'more' approach. This is the approach that, where deficits are identified in service supports, those who are at the controls believe all that is required is the creation of more principles, more standards, more strategies and more colourful documents.

The 'more' approach is possibly driven by expediency, avoidance and a sense of 'mateship' at the top. Some might even say there is a cosy relationship between the triad of the Department of Human Services (DHS), service providers and the funded advocacy and complaints bodies. To advocate 'more' seeks to send a message that the composite of power brokers have rightly identified what needs to be done to improve some facet of the service system.

### The 'more' approach

The 'more approach' is in effect a cop-out. It is an approach that feeds egos and promotes a sense of wellbeing that something 'more' is being done to make things better for people with disabilities and their families. Yet, it is an approach that avoids responsibility and obligations. It is an approach where those responsible, and with the power, can promote themselves as the standard bearers of change and enlightenment.

### Whipped cream and strawberries

The *Learning from Complaints Occasional Paper No. 2* is a classic example of the 'more' approach'. Where, what it really

being stated is that all that is needed are more principles, more planning, more strategies and more, albeit better, communication. The writers of this response liken this to the flat pavlova that, although a cook's disaster, is smothered in a mountain of whipped cream then layered with sweetened strawberries to give the illusion that what lies below is the genuine product.

The products to promote what is necessary and mandated already exist in the disability sector; it does not need to be covered in cream and strawberries. The principle product is the Disability Act 2006 along with a myriad of supporting documents. Yet another document, such as the Occasional Paper, is not required.

What is required from those responsible for service monitoring, service funding, service delivery and the protection of rights, and principles, and standards, is - to use a good-old Australian saying – for them to just 'do their bloody jobs'.

### Jobs not being done

The Department of Human Services, as the monitor of Funding and Service Agreements, standards and quality audits, the principal funder and also as a service provider, is not doing its job. By blatantly allowing particular of their own staff, as well as particular service providers, to get away with not doing their job, DHS is failing people with disabilities and their families.

Particular service providers, through particular of their managers and staff, are not doing their job. By time and time again failing to meet their mandated obligations as articulated in the Disability Act they are failing the people they are supposed to provide services to and the families of those people.

And significantly, as the sponsor of the Occasional Paper, the Disability Services Commissioner is avoiding his responsibilities by effectively hiding behind the 'more principles and more strategies' approach. So, the question must be asked as to whether or not the Commissioner is doing his job?



### **What do families want?**

Families do not need more whipped cream and strawberries; they want a 'better' pavlova base. They want people to do their jobs. Therefore, there is a danger in telling families that more principles and more strategies are the answer.

The writers of this response paper fully acknowledge and understand the background to the publication of Occasional Paper 2. They also fully support the desired practice of disability service providers acknowledging and working positively with families of adults (and children and young people) with a disability. However, despite agreeing with some comments in the *Learning from Complaints Occasional Paper No. 2*, the authors of this response submit that apart from the Occasional Paper giving the false illusion that all will be well if only the principles and strategies as detailed in it are applied, there are also a number of matters on which they consider the paper is deficient.

The fact that this paper is identified as being for families of **adults** with a disability is indicative of "the elephant in the room" – there is no explanation from the DSC why the paper is restricted to adults. Perhaps it is that upon turning 18 years of age a person is legally considered to be an adult and hence their own decision-maker and independent. Consequently, there is a belief, an attitude, which permeates the disability sector and service providers that there is no need to involve other people in the provision of services to adults with disabilities – and other people have no right to be involved. In effect, families can be shut out.

### **Yet more principles**

Of most concern is the paper's promotion of the idea that yet more principles and more strategies are required in order to get service providers, including the Department of Human Services, to do their job and meet their obligations under the Disability Act 2006. By, in effect, telling families that it will be through the development of another set of principles and strategies that "constructive relationships between

families and services providers" will somehow become the magic wand, this ignores three critical truths.

### **Three truths**

The first is that the Disability Act 2006 has included in it a substantial list of principles and a very clear set as applying to how disability services providers are required, by law, to regard families.

The Occasional Paper fails to emphasise and promote this expectation.

The second is that there are already in existence Quality Standards, which are audited; Funding and Service Agreements; a mountain of guidelines and policy and practice documents, and the provision to monitor and require adherence.

The third is that the Disability Services Commissioner already has within his authority the power to significantly influence the way services and supports are delivered.

### **Why isn't it happening?**

The critical question is – Why is it that service supports and protective mechanisms are not happening, as they should?

The answer is clear, and as noted further above, it is primarily because people are not doing their jobs as they ought to be. Additionally, it is because communication is promoted as the problem rather than acknowledging poor management, lack of effective supervision, and a failure to take action when transgressions are identified, as the problem.

The 'softly-softly no fault' approach, while perhaps promoted as the way business should be conducted in the disability sector, has clearly not worked.

Those who cannot, or refuse to, do their jobs must be excised from the system.

### **Why not promote that already existing**

The Occasional Paper is mindful that, "priority must always be placed on maximising the decision making, choice



and control by people with disabilities about their supports". And, given the belief that disability service providers need to ensure "families and other natural supports are encouraged and supported to be actively involved" - then, apart from applying the 'more' concept, why is it that the Learning from Complaints Occasional Paper No. 2 has not promoted what already exists as the basis for "maximising decision making and choice" and for "expectations" as applying to families, as already required by the Disability Act?

**A legitimate concern**

The writers express their concern that the Occasional Paper may act as a

diversion from the real issues associated with support services, family engagement and complaints investigation and management.

Until such time as the mandated requirements associated with support service provision, family engagement and complaints investigation and management are practised, as they ought be already, then there must be little expectation that another set of principles and strategies will cause any real changes to current practices.

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## **Part A: Critical comment and platform considerations**

In this section of the response the authors provide an overall comment in relation to what they submit represent the critical issues to be raised in the context of the Occasional Paper. The authors of this response therefore highlight what they argue represent platform considerations.

The authors submit that the following matters have import, not just in the context of the Occasional Paper, but also in the broader context of disability service provision and complaints management, which they argue has a direct relationship to the content and outcomes of the Occasional Paper. Therefore, while the authors contend that the matters and outcomes addressed in the Occasional Paper are important in their own right, nonetheless they also strongly contend that there must be a full and frank acknowledgement of the matters detailed below.

They argue the matters detailed provide the platform on which service provider-family relationship and complaints management must be based. The authors further argue that unless these platform issues are fully acknowledged and practised, then it is reasonable to conclude there will be little real change in the relationship between many families and many service providers, including the Department of Human Services.

On the matter of real change, the authors note it is over a quarter of a century since the inception of Victoria's Intellectually Disabled Persons' Services Act 1986 and the Federal Disability Services Act 1986 (and consequently Victoria's Disability Services Act 1991), and over seven years since the current Disability Act 2006 came into force. Additionally, it is also important to note that many services providers have been operating for upwards of 50 and 60 years, and in some cases more. It is somewhat ironic that it was families who created many of what used to be known as Day Training Centres, which then morphed into many of today's services. The importance of these facts is that despite having had a legislative framework in place for over 25 years and having had principles, rights and mandated roles and responsibilities for service providers for all those years, here we are in 2014 still talking about "developing policy principles and strategies to support families". It therefore seems reasonable to conclude this points to a significant failure of service providers, the protective mechanisms and the bureaucracy.

### **1. Where are the families?**

The authors of this response express their disappointment, and indeed concern, that the Family Engagement Reference Group did not appear to have included a family representative without any affiliation. Although the authors acknowledge that it may be argued the representatives from the Association for Children with a Disability, Carers Victoria and VALID represented families, it seems reasonable to conclude these representatives may not have had direct service involvement, as a family member, with a service provider. In any event, however, they were there representing their particular entity and not as an independent family person.

Given the project was specifically about families and service providers, and noting that service providers were represented by Yooralla, Peninsula Access Support and Training, Melba Support Services, Sunraysia Residential Services, Villa Maria, National Disability Services, the Department of Human Services (DHS), the Disability Services Commissioner's Board, the authors contend that the failure to include non-aligned family members represents a significant oversight.

Additionally, it is also noted that there was no representation of cultural diversity. As such the authors also argue that in today's multicultural society this also represents a significant oversight. Further, of the 14 members of the Reference Group it is also noted there was not one male person.



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Given the size of the group of 14, comprising two consultants, two DHS representatives, five funded service providers and five what might be defined as non-direct care agencies, the authors of this paper are highly critical of what they see as an imbalance in representation. They suggest that the failure to include non-aligned family representatives is a slight to families.

One is reminded of Michael Leunig's cartoon about No Ducks, where the sign The Great Important Conversation is on a building where people are shown as deep in conversation. Outside is Leunig's simple person with a duck, and the sign on the door reads "No Ducks Allowed". Michael Leunig described the "No ducks" drawing in terms of "how it seemed there is a very important public conversation going on in which all the important things are being discussed by all the important people." He pointed out that there they are, the same old faces; the same experts waffling on energetically and taking up a lot of space and attention. And as he queried, "What place has a lovely simpleton with a duck amongst such esteemed and glamorous minds?" (The Big Issue, 20 Nov – 3 Dec 2012). This is like the family engagement conversation which apparently has gone on – where there just needs to be another sign, "Sorry No Families".

The authors note reference in the paper to consultation with stakeholders and expect this may be used as an argument to rationalise the non-inclusion of non-aligned family representation on the Reference Group. While the authors comment on this in Part B of this response, given that the Occasional Paper purports to be aligned as a research activity they feel obliged to also make comment on it in this section of their response. The responders question – Why did the Reference Group not see fit to include anywhere in their paper any form of tabulation as to the nature of the consultative process?

At the very least it seems reasonable to expect some effort would have been made to detail the number of parties consulted, classified into families and other specific groups, a breakdown of the nature of the feedback, a distribution of the types of issues, comments made relative to accommodation services, day services and other services and the geographic spread of those consulted. No such information was provided.

### **Contention**

The writers contend that continuing to treat families as though they are simply sponges available to soak-up the pronouncements of the knowledgeable experts goes little way to truly understanding how families feel and think, and the real battles faced by many to be acknowledged, heard, and for their views to be considered. The issue of family engagement is not simply only about the person with a disability. It is as much about recognising the rights of families also.

## **2. The concept of the learning cycle and roles and responsibilities**

As noted further above, the legislative platform on which disability service provision is based has been in place for over a quarter of a century. The roles and responsibilities and obligations of service providers are well established. The Office of the Disability Services Commissioner has been functioning since July 2007. The question therefore arises as to - How long does it take to get it right? What is it that service providers, those responsible for the protective mechanisms, and the bureaucracy still need to learn?

The authors suggest it is somewhat frightening to think that we still require initiatives such as that enacted through the Occasional Paper to get it right. And, while they acknowledge the functions and powers required of the DSC, as articulated on page 38 of the Occasional Paper, and which include review, improvement, training and research, the authors, nonetheless, suggest that the outcomes identified in the Occasional Paper point more to a failure of individuals



and entities to carry out their roles and responsibilities rather than not knowing what is required of them.

#### **Contention**

The writers contend that the failure of some agencies and some staff to positively engage families while ‘in part’ may be about not “recognising the role of families”, it is more about attitude, an unstated bias against families and the adoption of a siege mentality whenever questions are raised about the delivery of services.

#### **3. Application of the law**

The Disability Act 2006, under Section 5, is unambiguous in terms of the requirement of service providers with regard to families. In this section there is a mandated requirement to consider, respect, acknowledge and strengthen the roles and involvement of families. The Act is also unambiguous in terms of the obligations of service providers as detailed further in Section 5 and Parts 4 and 5 of the Act. Additional to these provisions the Act is also unambiguous in terms of complaints management. The Act is also unambiguous in terms of communication, the provision of advice, notification or information.

The Act is - L A W – law. Yet, despite this the law is frequently broken and it is this that concerns many families when seeking to address concerns with service providers. It is the attitude of some service providers, when questioned, that leads families to feel that they are not recognised and thus they feel disempowered. And, it is because those service providers failed to meet their obligations under the law that family frustrations arise.

The authors find it incomprehensible to think that after over 25 years of legislation associated with disability and with the current Disability Act having been in place for over seven years, that some service providers still ignore the law and the requirement of them to meet their obligations under the law. Further, reference to the Act does not feature prominently, if at all, as it should, in the DSC’s Annual Reports. It is incomprehensible as to why the DSC does not identify failure to adhere to the Disability Act as an underlying cause of complaints.

#### **Contention**

The writers contend that the law has little, if any value, if it is not enacted both to its letter and intent; and further, if not promoted as the vehicle of requirement by those who should be doing so, then those people are also failing in their responsibilities. If promotion of the law does not occur, and instead replacement non-mandated documentation is invented, then not only is the law a failure but so are those who should be ensuring adherence to it. This must be addressed, not through the invention of further principles and strategies promoted by the DSC, noting of course it is not the role of the DSC to create policy for agencies. What the Commissioner must do when dealing with complaints is name agencies when they fail to adhere to the Disability Act. From this perspective the Occasional Paper is a diversion.

#### **4. The language of disability**

In a recent email received by the authors from a mother who has a son in his 40s with a disability, the mother reflected in relation to developing Individual Support Plans (ISPs) that, “Not all carers have degrees and can understand all the things that have to be included in the ISP”. From the authors’ experience of working with families this mother’s comment about ISPs could very well apply to most other aspects of disability.

The language of disability has, over many years, become littered with an ever-increasing array of what the authors describe as ‘trick language’. That is language used in such a way so as to pretend issues are more complex than they are and



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therefore cannot be described using words we can all understand, but instead an explanation is required in order to explain what the words mean. Much of this language is overblown rhetoric created by academics and bureaucrats in order to give the illusion of development, innovation and progress. In some ways this is akin to a manufacturer reviewing a product's life cycle and determining whether a new name is needed, whether a new image needs to be created for the product, or to recycle it as if it were a completely new product. Then of course, whatever they decide it has to be wrapped-up into a giant marketing campaign. And, so it is with the language of disability.

### **Contention**

The writers contend that it is often the language of disability that is, in a way, manufactured by academics and bureaucrats, that confuses and adds little value. Therefore, the propensity to use what might be described, as 'formula language' must cease and instead the language of existing legislation must be applied in the operational context of service provision and working with families. Comment on particular language used in the content of the Occasional Paper will be addressed in the Content Analysis section of this response.

## **5. The matter of policy principles**

Since the introduction of the Intellectually Disabled Persons Services Act (IDPS) in 1986 the pathway of every new direction since has become lit by what might be called guiding principles. The IDPS Act had included in it 14 principles. The current Disability Act has a detailed set of principles in Section 5, which address the rights of persons with a disability, the obligations of service providers and a set specific to persons with intellectual disability. It also has planning principles in section 52. The National Disability Insurance Scheme Act 2013 has several principles included among its pages.

Additionally, there have been a number of other publications that make mention of principles.

### **Contention**

The writers contend that what is apparent in the Occasional Paper is the constant reinvention of principles, and that those who should be are not putting the Disability Act 2006 to the centre of their thinking when service provision is under discussion. It is particularly regrettable that the Office of the Disability Services Commissioner, whose functions are established by this legislation, is apparently unable to promote the Disability Act 2006 as the platform determining how services operate.

While the DSC 2012-13 Annual Report makes mention of the principles having received overwhelming positive support from all relevant stakeholders, it is unlikely that the principles were presented as a "choice" between those in the Disability Act 2006 or those in the Occasional Paper.

### **Contention**

Despite the proliferation of principles, and acknowledgement in the Occasional Paper by reference to principles being in a number of publications including legislation, the writers of the Occasional Paper have still seen fit to include yet another set of principles. In effect their broad based acknowledgement of the various publications unfortunately fails to emphasise that it is the Disability Act 2006 that articulates the mandated principles. Essentially, therefore any other principles are subordinated by the Act.

The authors of this response contend that enough is enough. It is not a dearth of principles that is the problem. Part of the problem is that the principles that are mandated through legislation are not being applied, as they should. Hence, the



authors of this paper say: Stop the nonsense of creating more and more principles and seeking to, in effect, reinvent the wheel.

## **6. The process of family engagement**

The Disability Act 2006, by reference to Principles 5 (3) (h) to (k) inclusive, addresses what is essentially the rules applying to family engagement. Yet, despite this, the Occasional Paper seems to argue the need for 'strategies'. The authors argue the Occasional Paper, in promoting the five principles and associated strategies, is nothing short of a cop-out and bureaucratic gobbledegook.

The authors argue that the real, and hard-core, issues associated with family engagement have largely been ignored by the Reference Group. The basis of this position being that, if as found or at least inferred by the Reference Group, service providers still need to have the principles of positive family engagement explained and told how it should be practised, then this must be considered as a serious matter that requires a far more assertive comment than the safety conscious commentary and 'solutions' as made in the Occasional Paper.

It almost goes without saying that positive family engagement is a cornerstone of providing service supports for people with a disability, excluding of course those circumstances where the person with the disability may freely choose not to have family involvement. Thus, given the promotion of another set of principles and associated strategies aimed at increasing best practice the question must be asked – Why does the Reference Group believe that this additional layer will encourage service entities, in particular, to do what the rules already require? Further, what is it that some service providers, and in particular some direct service staff, find so difficult to understand and actually practise?

### **Contention**

The authors of this response paper contend that until such time as the hard-core issues are addressed, the application of the findings of learnings from complaints will simply paper-over the real issues. As such they will continue to largely be ignored, as is currently the case.

In the authors' view the core issues that underpin the current dysfunction in terms of the manner in which some service providers engage families are five and are as detailed below:

- (i) Knowledge, promotion and practice of the existing mandated requirements
- (ii) Documenting mandated requirements in a service provider's policy and practice manual
- (iii) Effective management and supervision
- (iv) Doing 'your' job
- (v) The DSC acknowledging more communication and more planning is not the answer to all transgressions

## **7. Facts and figures**

The Occasional Paper, in various parts, makes reference to particular data. As often quoted in reference to data, there is the cliché, "There are lies, damned lies and statistics". It should be of no surprise to most that statistics, as in data, figures and so-called facts, can be used to mislead, if not deliberately, at least inadvertently. In a paper entitled – *Let There Be Light – Complaints Management – Process and Practices Victorian Disability Services Commissioner*, the authors of that paper, and also this response paper, made comment in relation to the DSC's 2012 Annual Report.



In part they stated:

*"While it is reasonable to suggest that the 2012 Annual Report met its legislative requirements, the writers question whether the report is what might be described as a truly reflective and incisive document.*

*By way of example the writers argue that despite the proliferation of data and tables, the report lacks transparency in that it conveys mixed messages in terms of the resolution of complaints. Further, the writers also argue that the report has failed to reflect on the likely reasons why the particular figures may be as reported. The writers submit that an Annual Report provides a creative opportunity to express what a service has learnt in the previous 12 months, and how it might add value in the coming 12 months. The DSC 2012 Annual report fails to exploit either of these opportunities."*

In his response letter dated 29 November 2012 to a covering letter sent by the writers on 22 November 2012 along with a copy of the paper, the Disability Services Commissioner stated, *"I am confident, based on the feedback from people with a disability and those who have brought issues to us, service providers and other stake holders that approaches taken by my office to dealing with complaints and capacity development are sound. This includes our focus on safeguarding and advancing rights of people with a disability and creating sustaining long term organizational cultural changes within the disability sector."*

Given the Commissioner's confidence – How come the need for the Occasional Paper as published in January 2014? Apart from this question, however, the Commissioner ignored issues raised by the writers in their Let There Be Light paper. It is therefore of concern that the Occasional Paper details some figures that, in the writers view, still lack transparency and thus fail to tell the real story.

### **Contention**

The real story of the failure to engage families effectively, and the real state of complaints, is either being buried in the published figures or simply ignored. Nowhere, to the authors' knowledge, are there recorded any figures that reflect issues such as an absence of knowledge, the level of staff incompetence, the part played by arrogance, staffs refusal to abide by program agreements, and, the most significant issue, duty of care transgressions. It is these issues that provide the canvas on which the enduring picture of deficits in family engagement should be recorded.

Comment on particular figures is provided in the section below.

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## Part B: Content Analysis

The authors' response to the specific contents of the Occasional Paper is detailed in the tables below.

<b>Part 1: What we've learned</b>		
<b>Page</b>	<b>Content Focus</b>	<b>Responders' Analysis</b>
3	The Commissioner's call to the disability sector to support the development of policies and practices etc.	<ul style="list-style-type: none"><li>While the responders echo the Commissioner's call for <b>practices</b> aimed at supporting families to be embraced by the sector, they challenge the need for <b>policies</b> to be developed, arguing the Disability Act already reflects the way service providers are required to treat families.</li><li>Further, the responders also query whether the Commissioner, himself, seeks to pursue such deficits as vigorously as he might when dealing with complaints referred to his office. In other words – How forthright is he and his officers in challenging agencies when such deficits are identified? And – Why does the Commissioner not name those agencies that transgress their obligations to families in his Annual Report?</li></ul>
3	The concept of families	<ul style="list-style-type: none"><li>While the responders do not disagree that families can include parents and siblings, they argue that families are not limited to these roles. The writers argue that recognising primary relationships is a key to improving family engagement - primary relationships such as mother, father, husband, wife, partner, brother, sister, aunt, uncle, son, daughter of the person with a disability – and the absence of these from the definition is a significant oversight.</li><li>They also query the inclusion of 'carers' as this is muddying the waters, especially as in the Act carers are identified separately to families, noting that including 'carers' was an amendment to the Disability Act with the passing of Victoria's Carer Recognition Act 2012.</li><li>The writers argue that language and statements which can be seen to limit the platform of "family" and its diverse primary relationships must be actively avoided.</li></ul>
4	The five key aspects	<ul style="list-style-type: none"><li>The responders must question as to whether the ODSC has sufficiently analysed what its experience has been. The writers suggest that based on what the ODSC has said, the experience, what they have learned, has actually been:<ul style="list-style-type: none"><li>- Some service providers do not recognise and respect the role and importance of families, and therefore are in breach of</li></ul></li></ul>



		<p>the Disability Act 2006</p> <ul style="list-style-type: none"><li>- Families are the makers of a significant number of complaints to the DSC</li><li>- Four forms of engagement typically occur between families and service providers – constructive, ad hoc, marginal, destructive (though it could be that these forms are an artificial construct of the DSC)</li><li>- Families and service providers may have differing expectations of the person with a disability and their support requirements</li><li>- Despite the promotion of "It's OK to complain" people are fearful of making a complaint</li><li>• What the DSC apparently has either not learned from its experience or is unwilling to state is that service providers are in breach of the Disability Act 2006.</li></ul>
5	Recognising the role and importance of families	<ul style="list-style-type: none"><li>• In recognising the existing legislation that highlights the importance of the role of families and details mandated requirement in dealing with families, the responders express concern that the Paper fails to pursue the matter of legislated requirements further.</li><li>• Thus, given the "in spite of" comment the responders query why it is that the Reference Group considers that the principles and strategies as detailed in the Occasional Paper will have more clout than legislation?</li><li>• The Occasional Paper claims that the important role that families play in people's lives has been recognised in the Carers Recognition Act 2012. This is incorrect, given that this Act only mentions family by reference to family day care and the Children, Youth and Families Act. Section 7, as referenced in the Occasional Paper as recognising families, is only about carers.</li><li>• On the DHS website in the disability information it uses the language "Carer and family support" and states "<i>This section offers information on the different types of supports available for families of children with a disability and carers of adults with a disability.</i>" While this might be considered a small example, it is nevertheless indicative that the Department has some problem in recognising families of adults with a disability. <a href="http://www.dhs.vic.gov.au/for-individuals/disability/carer-and-family-support">http://www.dhs.vic.gov.au/for-individuals/disability/carer-and-family-support</a></li></ul>



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		<ul style="list-style-type: none"> <li>• This is indicative that maybe DHS and other service providers have difficulties in recognising the existing principles in the Disability Act 2006.</li> </ul>
7	Patterns of enquiries and complaints data	<ul style="list-style-type: none"> <li>• The responders again raise question as to why it is the DSC persists in amalgamating "enquiries" and "complaints" as a major heading. They say, again, because this matter was raised with the Commissioner in a Paper entitled – Let There Be Light – sent to him in November 2012. Surely 'enquiries' cover a broad range of matters and are just that - 'enquiries'. The real data to be addressed is that of 'complaints'.</li> <li>• The responders contend that the significance of the above is emphasised by the paper's comment that, "The majority of complaints to DSC and service providers are about services provided to people with an intellectual disability." Hence, it seems reasonable to conclude that many would be a failure to meet duty of care obligations and/or are a breach of obligations under the Disability Act. Why therefore does the Commissioner not name the agencies concerned?</li> <li>• Given the reasonable likelihood that the same agencies, year after year, breach their service obligations, it is clear the Commissioner's approach of the path of least resistance is not working. Otherwise why the need for the Occasional Paper?</li> <li>• It is of interest that the Community Visitors in their 2012/13 Annual Report have shown the courage to name agencies.</li> <li>• The comment is made that the data provides a strong case for families having a say in the delivery of disability supports. The fact is that such data is not required – the Disability Act 2006 provides for families having a say in the delivery of disability supports.</li> </ul>
8	Characteristics of relationships etc.	<ul style="list-style-type: none"> <li>• While the responders would not oppose and indeed would support the comment made on page 8 that, "there are many examples of respectful and effective working relationships ..." this support is tempered by the consideration that people have a fear of complaining.</li> <li>• In recognising the above, and further, in assuming the DSC does have detailed data as to which agencies are at the top of the ladder in terms of complaints made about them, the responders query – As to why the Occasional Paper did not detail a breakdown as detailed in the box above.</li> </ul>

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		<ul style="list-style-type: none"> <li>• In terms of the questions posed by the DSC to service providers about working with families, this brings into doubt the efficacy of the DSC's guides and checklists for service providers, and the actual use of its products.</li> <li>• The key point is that if service providers had completed, say, even the DSC's quick checklist for their complaints system practice self-audit, many of the issues being raised around family engagement would have already been apparent and perhaps even addressed.</li> </ul>
9 & 10	<p>Characteristics of relationship</p> <ul style="list-style-type: none"> <li>• constructive</li> <li>• ad hoc</li> <li>• marginal</li> <li>• destructive</li> </ul>	<ul style="list-style-type: none"> <li>• The Reference Group's attempt to characterise relationship in the way they have is considered by the responders to be questionable.</li> <li>• In particular, the responders express concern as to the commentary detailed under the 'constructive engagement' and 'ad hoc engagement' headings.</li> <li>• The amalgamation of these two references seems to suggest that only constructive engagement is "respectful" and ad hoc is not.</li> <li>• On the matter of ad hoc engagement the commentary is misleading. Given ad hoc engagement does "appear to be the dominant form of engagement", the responders submit that it is wrong to suggest that this form of engagement is necessarily "without certainty and without consistency".</li> <li>• Indeed, even in situations where two parties communicate through only a few sentences about a singular one-off matter, there can be certainty and consistency.</li> <li>• In part, the responders submit that it is not surprising that ad hoc engagement is the dominant form. The problem with the commentary provided in the paper is what appears to be an inferred definition attributed to the word ad hoc.</li> <li>• It appears that the lack of a policy specific to family engagement is the DSC's critical analysis of what is lacking.</li> <li>• What the DSC is actually highlighting is that service providers are not adhering to the Disability Act.</li> <li>• Given that ad hoc, in effect, relates to what the responders contend is an action occurring on 'an as needed basis' it cannot be inferred, as indeed suggested in the paper, to not be "planned", "without certainty" or "without consistency".</li> <li>• The responders submit that the real issue about whether or not communication with</li> </ul>



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		<p>families is constructive is not that ad hoc communication cannot be constructive, but it is about attitude and skills of the agency's representative who is charged with the responsibility of communicating with a family member.</p> <ul style="list-style-type: none"> <li>• As noted in the paper, the House Supervisor within the context of supported accommodation is a key player.</li> <li>• The responders contend that despite the paper, on page 9, making reference to family members having reported concerns about House Supervisors and "the lack of engagement by senior management", the Reference Group failed to address such concerns except by way of saying service providers should have a policy engaging senior managers.</li> <li>• The responders argue that given these concerns were articulated by families, and clearly are of significant concern to a number of families, the Reference Group had a responsibility to provide a specific response about such matters as management training and position selection.</li> <li>• If it is that some staff in such positions are ignoring their position and statutory obligations, then why did the Reference Group not also include comment about performance management?</li> <li>• The responders are critical that the DSC has determined that constructive engagement requires documented explicit agreement between the service provider and the family.</li> <li>• It appears that such "constructive engagement" requires agreement as to how disputes will be addressed – yet the Act already requires that service providers must have and operate a system to receive and resolve complaints, and there is a penalty, which applies if they do not have this.</li> <li>• This "constructive engagement" also requires agreement as to the type, level and frequency of communication – this is nonsense, not the least because who knows what might come up in the future.</li> <li>• The over-arching question is: Why seek to duplicate the Act in yet another set of documentation when the Act clearly states what is required in terms of principles for service providers as to how they must provide services, the provision of information, ongoing support documentation, a complaints system etc?</li> </ul>
11	Differing expectations etc	<ul style="list-style-type: none"> <li>• The quote on this page, as attributed to a parent of a person with a disability, is argued by the responders to be much more</li> </ul>



		<p>than just an example of "differing expectations".</p> <ul style="list-style-type: none"><li>• The responders' experience of working directly with families strongly suggests that, at least in terms of supported accommodation, matters of health and welfare can reasonably be concluded to be among the most frequently raised issues.</li><li>• The responders contend that while it might be there are "differing expectations" the real issue is that of a failure to staff and agencies to meet their duty of care obligations.</li><li>• Thus, rather than simplistically suggest that differing expectations can be resolved by a willingness to "talk openly and respectfully over a number of conversations", the responders argue that where duty of care is not met it is not simply a matter of more conversation, it is a matter that staff meet their duty of care and managers ensure they do.</li></ul>
12	People's fear of making a complaint	<ul style="list-style-type: none"><li>• While the responders acknowledge this finding they question whether any information was obtained explaining the view that some people give up making complaints because nothing ever happens.</li><li>• If a learning from complaints has been that people are (still) afraid of making a complaint, a question arises as to what, in the first instance, is the DSC is doing to monitor this?</li><li>• The Disability Act is quite clear that service providers have a duty to take all reasonable steps to prevent adverse effects because a complaint has been made. What is the DSC doing to monitor what service providers have in place to uphold this duty?</li><li>• In terms of upholding the right to complain, the DSC emphasis on there being a constructive working relationship (as defined by the DSC) sits oddly with the Disability Act's requirements of service providers.</li><li>• It is as if the DSC is saying "You have a right to complain only if you have an explicit agreement that documents the mutual expectations and roles of the service provider and the family in terms of support arrangements for the person with a disability."</li><li>• The responders emphasise that the fear of making a complaint indicates that there is a long way to go to achieve effective monitoring of service providers complaints systems.</li></ul>



<b>Part 2: Supporting constructive engagement between families and service providers</b>		
<b>Page</b>	<b>Content Focus</b>	<b>Analysis</b>
13	Supporting constructive engagement etc.	<ul style="list-style-type: none"><li>• Who were the "stakeholders" who "agreed that a set of policy principles was required"?</li><li>• How much influence was exerted by the Reference Group to elicit this alleged response of stakeholders?</li><li>• As noted further above there is no advice in the paper to identify who were the "broad range of stakeholders" relevant to the disability sector.</li><li>• The premise underlying the inclusion of the principles and strategies detailed in the paper, while laudable, are argued by the responders to be unnecessary window dressing.</li><li>• The fact is that one of the objectives of the Disability Act, (4) (e), requires the provision of high quality disability supports, and thus given the purpose of the Act relates to "persons with a disability" by its very nature the Act does "place the person with a disability at the centre of" supports provided to him or her. As such the laudable premise underpinning the principles and strategies in the paper is superfluous.</li><li>• Additionally, the Act also requires the active participation of the individual with a disability in decisions affecting his or her life – principle 5(2) (e)</li><li>• Thus again, the reference to respecting a person's right to be "actively engaged" is also considered as window dressing aimed at giving credence to the inclusion of the principles and strategies.</li></ul>
14	Policy principles	<ul style="list-style-type: none"><li>• Again, the responders note there is nothing new in the Preamble.</li><li>• While the Preamble mentions the United Nations Convention and the recognition of families, no mention is made of the Disability Act 2006 and its recognition of families.</li><li>• Indeed, given the principles as articulated in the Disability Act, noting yet again these represent the law, what is it about the principles detailed in the paper that the Reference Group believes will instil in recalcitrant service providers and staff a new found desire to toe the line?</li><li>• It is not more policy principles that are required. Instead DHS must insist on their own services and funded agencies meeting their obligations under the Act; managers must monitor, manage and demand</li></ul>



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		adherence to the law; and the DSC must acknowledge that not all complaints are simply a problem with communication, and staff and agencies do err. As such, when they err, the DSC needs to call them on it.
15	Policy principles	<ul style="list-style-type: none"> <li>• An examination of these five principles shows that, in effect, there is nothing in them that is not in some way addressed by the principles in the Disability Act.</li> <li>• The question therefore arises – Why yet another set of principles?</li> <li>• Were the principles of the Disability Act put to the stakeholders as being appropriate for the task?</li> <li>• Were the principles of the Disability Act rejected by stakeholders as being appropriate for the task?</li> <li>• In the context of the law the responders also ask - Why did the Reference Group not see fit to detail and promote the Act's principles in the Occasional Paper and instead create their own?</li> </ul>
16	Strategies for service providers	<ul style="list-style-type: none"> <li>• The writers of this response ask whether or not 'attitude' and absence of goodwill were also identified as common features in the matters brought to DSC.</li> <li>• The writers argue it is too simplistic to suggest that while it may be that the surface issues appear to be about planning and misunderstandings, the matter of negative and pompous attitudes and an unwillingness by service providers to adhere to the Disability Act are likely to be in the main the core issues.</li> <li>• For the Reference Group not to have investigated these factors must be a significant deficit.</li> <li>• The DSC makes mention that the strategies proposed are based on dealing with more than 3,700 enquiries and complaints – as if this gives them great expertise – when in fact there are considerably fewer complaints to give depth to the DSC's experience.</li> <li>• Also, that the strategies are based on the Annual Reporting from service providers.</li> <li>• If indeed the strategies are based on misunderstandings about what supports will be provided, how they will be provided and at what cost, then one must ask how well service providers are meeting the requirements of the Disability Act for preparing support plans, as required for ongoing services, and communicating these support plans as required under the Act's provision of advice and notification requirements.</li> </ul>



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		<ul style="list-style-type: none"> <li>While the DSC seems to emphasise communication deficits, it needs to put these in the context of the Act's requirements regarding advice and communication and identify that the Act is being breached.</li> </ul>
<b>Note:</b> Pages 17 to 30 have been amalgamated as below with reference only being made to particular strategies, noting again the writers of this response submit that the strategies are a diversion from the real issue of people being required to do their jobs. And a diversion from service providers doing what the Disability Act 2006 requires.		
17	Board representation	<ul style="list-style-type: none"> <li>The writers of this response submit that this strategy is straying into an area that is outside the jurisdiction of the responsibility of the DSC.</li> <li>The argument that families should be represented on a Board because families make complaints, which would otherwise not have been heard, is unequivocal nonsense.</li> </ul>
18	Policy and procedure	<ul style="list-style-type: none"> <li>The strategy of itself suggests that service providers are not adhering to the Disability Act.</li> </ul>
19	Communication and language	<ul style="list-style-type: none"> <li>Language is important and is often used by service providers to confuse, control and rationalise.</li> </ul>
20	Active participation	<ul style="list-style-type: none"> <li>Already many families are in effect running a small business by having a son or daughter with a disability. To suggest further participation seems to ignore the reality of the stress pressures already existing for many families.</li> <li>More does not necessarily mean better. Agencies need to be efficient in their dealings with families and avoid the meeting treadmill, and the paper and plans treadmill.</li> </ul>
21	Interview panels	<ul style="list-style-type: none"> <li>The writers challenge the strategy of family members being on interview panels.</li> <li>The family or the person with a disability does not need to be on a panel to have a final say over who provides their supports.</li> <li>The final say comes when a person is considered unsuitable by the person with a disability and/or their family – this comes down to who has the say in “firing” a person.</li> </ul>
22	Feedback to stakeholders	<ul style="list-style-type: none"> <li>The writers support this as a ‘must’ – See comment for page 36.</li> </ul>
23	Reluctance to make a complaint	<ul style="list-style-type: none"> <li>Reluctance is also sometimes because nothing happens or because the process is so elongated many families in effect give-</li> </ul>



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		<p>up.</p> <ul style="list-style-type: none"> <li>• The ODSC appears to be a major contributor to dealing with complaints on the treadmill and applying the 'forever' approach.</li> <li>• While in this strategy there is mention of the Disability Act principles and requirements, what is needed is more than the DSC having a belief that service providers have a responsibility to overcome the fear of complaining. What is needed is for the DSC to monitor how well service providers do this.</li> <li>• For example, how many service providers have their complaint and feedback contacts or forms easily found on their websites? And as mentioned previously, what do service providers actually do to uphold their duty to take all reasonable steps to prevent adverse effects when a complaint is made.</li> <li>• While the Occasional Paper notes that the DSC made 250 visits to service providers in 2012-13 to inform their understanding of existing practices in the sector, it appears that these visits did not make assessments as to how effectively providers were fulfilling the requirements of the Act for their complaints management system.</li> </ul>
24	Strategies for the delivery of supports	<ul style="list-style-type: none"> <li>• In terms of service providers, what these strategies indicate is a failure to adhere to the Disability Act regarding both on-going support and planning and the provision of information.</li> </ul>
25	Differing expectations	<ul style="list-style-type: none"> <li>• Perhaps so, but a failure of staff and agencies to meet their duty of care is often ignored as being the real issues.</li> <li>• The DSC in his Annual Report does not mention duty of care, yet duty of care, if not met, is negligence.</li> <li>• Until duty of care is rightfully put at the head of queue then papers such as the Occasional Paper will continue to miss the point that families rightfully have the expectation that their sons and daughters will have their duty of care met.</li> </ul>
26	Lack of clarity	<ul style="list-style-type: none"> <li>• If anyone in the disability sector, including bureaucrats and any service provider, after disability having been in the spotlight for over a quarter of a century and the introduction of the Disability Act in 2006, still does not understand their responsibilities and roles then they should not be working in the disability field.</li> <li>• The Occasional Paper ignores this.</li> <li>• It is interesting that the paper states that an area of discussion needs to be the service provider's legislative obligation to promote</li> </ul>



		<p>the person's independence and dignity of risk, particularly in relation to decision-making. This is indicative of an attitude that families want to hold back the potential development of the person with a disability.</p> <ul style="list-style-type: none"><li>• While it is all very fine to espouse the virtues of dignity of risk, it has to be tempered with the concept of what is reasonable. (It is of interest that this is recognised in the NDIS Act.)</li><li>• But, of even greater significance is the requirement to understand that a care provider who breaches their duty of care responsibilities can, under the law and as defined in the Wrongs Act 1958, be found to be negligent in the eyes of the law.</li><li>• The writers of this response paper suggest that any consideration between a finding in favour of dignity of risk, where negligence is proven, would be most unlikely.</li></ul>
<p><b>Strategies and resources for families, pages 31 – 36</b></p> <p>An amalgamated comment is provided below in relation to pages 31 to 36, Strategies and resources for families.</p> <p>The DSC makes the opening comment that "It is evident to DSC that many families are unsure of their right to question how their family member's supports are to be delivered and the level of input they will be able to have into those supports". This clearly indicates that service providers are not adhering to the Act – otherwise families would not be unsure of their right to question a service provider. Essential to analysing what might be otherwise described as communication issues is a lack of adherence by service providers to the Disability Act.</p> <p>This indicates that families are not being informed of and making use of the provisions of the Disability Act, in particular the ongoing support and planning sections and the complaints sections – or if they are being informed, it is not being done in such a way that it is seen as providing the foundation for the disability services their family member receives, and the interactions between the various parties involved.</p> <p>While a legislated function of the DSC is to review and identify causes of complaints and suggest ways of removing and minimising those causes, one must question why the DSC sees the need to develop a stand-alone resource for families of adults with disabilities. What is obviously missing from the equation is advocacy support for families, and the DSC should direct its efforts to a holistic solution to the difficulties it maintains it sees families as having, rather than provide a "solution" which makes the problems family-centred rather than system-centred. The DSC would be better off recommending funded family advocacy.</p> <p>Perhaps the DSC is well-intentioned in hoping that its resource will be preventative of complaints arising, and a training resource about the prevention of complaints. However, the DSC needs to be aware that it is setting itself up as being particularly judgemental of families, in that if a family were to answer "No" to any of the questions posed in the five areas it presents to families, then it appears that the DSC would consider the family to be at fault, and negligent in its responsibilities. Also, there seems to be an attitude that the questions asked</p>		



will be of importance to families. Who decided that this question and answer format would best serve families, and that these were the critical questions which needed to be asked and answered by families?

If these are areas and questions of such critical importance, one must ask why the service providers were not given the same strategies and resources, that is, have the five question and answer areas rewritten as "strategies and resources for service providers". Rewriting the questions in this way is an illuminating exercise, as such questions focus attention on what the Disability Act actually requires of service providers. I

Further, while the DSC may see itself as having a role in building the social capability of families to navigate the disability service system, the DSC needs to have a better understanding and appreciation of the shoals which can confront families when dealing with disability service providers before it becomes a font of knowledge and advice. The DSC may well have dealt with over 3,700 enquiries and complaints. However, its ability to get to the core of what is driving the enquiries and complaints is questionable.

The DSC must give far more thought and focus to what it suggests by way of removing and minimising causes of complaints. Perhaps if it were to use its Annual Report to Parliament to name and shame providers who do not adhere to the Act, or conduct investigations, or insist that providers meet their duty of care, or monitor that providers have a readily understood and accessible complaints process, or to actively support there being funded family advocacy, then there may be a better likelihood of removing and minimising causes of complaints.



Appendix A:		
Page	Content Focus	Analysis
38	Complaints and enquiries	<ul style="list-style-type: none"> <li>Section 16 (a) and (b) of the Disability Act is unambiguous in its reference to "complaints". Therefore, why has the Occasional Paper seen fit to amalgamate enquiries with complaints and quote the figure of 3,700, combined, since July 2007 without providing a figure for each category? The other anomaly is that when one digs down into the figures quoted, these include in-scope and out-of-scope inquiries and complaints. Then the figures are further muddled by being reported as in-scope complaints resolved. So, for example, in 2012-13 there were 908 inquiries and complaints, of which 705 were inquiries and 203 were complaints; and a total of 514 were in-scope, but there does not appear to be a report of inquiries and complaints separately. The number of in-scope complaints closed is reported at 156, or 17% of the 908 for 2012-13; and 140, or 17% of 832 for 2011-12. Extrapolating from the past two years, it is reasonable to conclude that <b>of the 3,700 inquiries or complaints only 630 have been closed in-scope complaints, averaging two a week.</b></li> <li>The report gives no breakdown of who made the in-scope complaints closed. It would be relevant to know how this lines up against the approximately 50 per cent of inquiries and complaints being made by families, which includes relatives.</li> <li>Further, given that the current Annual Report states that 29% or approximately 45 of 156 complaints reviewed were either only partially resolved or not resolved at all, the writers therefore query why there was not one single investigation undertaken as was also the case for the previous reporting year. Noting that not to have done so seems to suggest that the DSC has been prepared to consign approximately 45 complaints to the 'too hard basket'. The authors of this response suggest that to ignore even one, let alone 45, cases by not investigating is a travesty of justice.</li> <li>The significance of the above relates to the argument that despite there being a legislated provision for the undertaking of investigations the Commissioner refuses to apply this provision and instead seeks to promote the soft option of more principles and strategies for others to apply.</li> <li>Indeed the Commissioner, in his 2012/2013 Annual Report in effect abrogates his legislated investigative authority by stating, "<i>No complaints were referred to investigation by</i></li> </ul>



		<p><i>DSC in 2012–13. However, in response to DSC's recommendations and setting the terms of reference, service providers undertook investigations, broader service reviews or 'root-cause analysis'. The findings of these investigations or reviews can form the basis of agreements reached on actions to resolve the issues and improve services. The DSC has found these approaches to be an effective way of addressing issues of concern and promoting learning from complaints by service providers."</i></p> <ul style="list-style-type: none"><li>• The writers of this response find this a concerning action and ask – Why does the Commissioner not see fit to exercise his authority under Section 118 (1) (a) of the Disability Act?</li><li>• Further, why does the Commissioner see it as being OK to, in effect, delegate his authority under the Act to service providers to investigate themselves, when the complaint was made to him about the service provider?</li><li>• The writers of this response submit that not only is this approach a contravention of the Act, but also it is a 'slap in the face' to the complainant.</li><li>• Some families with whom the writers have spoken have asked whether or not the Commissioner's obvious reluctance to investigate is either because he and his staff do not have the necessary skills, or because the Commissioner wants to preserve his mutually supportive relationship with DHS and funded service providers.</li><li>• The writers of this response argue that the Commissioner's rationalisation as provided in the current Annual Report and as noted above, does not stand up to scrutiny. Apart from the fact it ignores his responsibilities under the Act, the contents of the Occasional Paper also belie this rationalisation.</li></ul>
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## Concluding Comment

So, what is it that can be finally said, as a concluding comment, about the efficacy of Occasional Paper No. 2?

The authors of this response direct the readers back to their opening remarks. In summary, the authors emphasise three over-arching areas where they submit the Occasional Paper and the DSC, as the paper's sponsor, have failed

1. Occasional Paper No. 2 has failed to emphasise that a law, as in the Disability Act 2006, exists; and that this law articulates the mandated requirements in relation to family engagement and associated matters. As such, by advocating the 'more' principle of yet more principles and more strategies the Occasional Paper has sought to provide a smoke screen, as a cover up for the failure of individuals and agencies, including DHS, in not adhering to the law.
2. Occasional Paper No. 2 has failed to identify the inability or reluctance of individuals and agencies, including those charged with the monitoring, directing and protecting, to do their jobs, as the root cause of the current failures to recognise and positively engage families.
3. Occasional Paper No. 2 has failed to identify an absence of strong and decisive leadership as an element in ensuring individuals and entities adhere to the law and do their jobs. By failing to identify the need for strong action when things go seriously wrong, and instead having opted for more principles, more remedial strategies and more talkfest, the Occasional Paper has gone down the non-confrontation path.

The view of the DSC as to what families must do to be engaged – which translates into more paperwork and more plans and more meetings – is only adding to the weight that families already carry as they make their journey into, along and through the disability service system. Surely the aim of those who are paid to work in the disability sector must be to lessen the weight, not add to it. If for no other reason, this Occasional Paper must be rejected for the weight its strategies add to families.

The whole matter of family engagement must be rethought. The DSC must go back to the drawing board and put adherence to the Disability Act 2006 front and centre by writing an entirely new paper; or, if unwilling to do so, then withdrawing the current inadequate Occasional Paper No: 2.

Deliberations as to what the DSC, his staff, and service providers; including DHS; must do in order to carry out their functions as required by the Disability Act must be placed under the spotlight and that must become the focus. The outcomes of such deliberations must be to the forefront of the rethinking.

Not to do so will continue to consign families to being the load carriers, while at the same time letting the lawbreakers off the hook.



**JacksonRyan Partners**  
*A Business Unit of*  
*Max Jackson & Associates*

ABN 50 086 394 676

**Head Office**  
1/98 Wells Street  
Southbank VIC 3006  
Telephone: (61-3) 9077 4152

Max Jackson  
Mobile 0413 040 654  
Email: max@jacksonryan.com.au

Margaret Ryan  
Mobile 0412 409 610  
Email: margaret@jacksonryan.com.au

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**A JacksonRyan Response Paper:** The Danger of Telling Families that More Principles and More Strategies are the Solution.

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