

Learning from Complaints  
Occasional Paper No. 2

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# Families and service providers working together

Developing policy principles and strategies  
to support families of adults with a disability  
and disability service providers to work  
more effectively together

**February 2014**

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### Disability Services Commissioner Family Engagement Reference Group

Professor Christine Bigby  
*La Trobe University*

Jennifer Boulton  
*Yooralla*

Terri Carroll  
*Peninsula Access Support  
and Training*

Sarah Fordyce  
*National Disability Services  
(Victoria)*

Dr. Chris Fyffe  
*Disability Consultant*

Jill Gardiner  
*Department of Human Services*

Liz Kelly  
*Disability Services Board*

Penny Kendall  
*Melba Support Services*

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*Association for Children  
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Christine Scott  
*VALID*

Heather Thompson  
*Department of Human Services*

### Learning from Complaints: Occasional Paper No. 2 Families and service providers working together

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# Learning from Complaints

## Occasional Paper No. 2

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## Foreword

We are pleased to present this second paper in our series of Occasional Papers on 'Learning from Complaints'. This paper addresses the issue of families of adults with a disability and service providers working together.

There are many examples of families and service providers working effectively together in the best interests of the person with a disability. However, a consistent theme in our work has been the resolution of complaints that have arisen from a lack of consultation and agreement between families and service providers on how supports will be provided and on their respective roles in providing those supports.

In developing this paper we are mindful of the maxim 'nothing about us, without us' and the priority that must always be placed on maximising the decision making, choice and control by people with a disability about their supports.

However, we are also mindful of those people with a disability who may have limited ability, or require support, to advocate effectively for themselves. We believe that for these people the involvement and support of family and other natural supports is both integral to their long-term wellbeing, and a critical safeguard in the provision of supports.

In consultation with a range of people with a disability, families, service providers and academics we have developed and proposed a set of policy principles and practice strategies that we believe will support families and service providers to work more effectively together.

Our goal in producing these papers is to identify key considerations for practice and service improvement, and to suggest ways of addressing some of the underlying causes of complaints, in order to promote and protect the rights of people with a disability and to contribute to effective preventative strategies. We do not claim to cover all aspects of the topic but instead aim to stimulate further thought, discussion and action based on important lessons from matters we have dealt with.

I encourage you to consider this work and invite your feedback on this important issue.



**Laurie Harkin AM**  
Disability Services Commissioner

## About this paper

The Disability Services Commissioner (DSC) calls on the disability sector in Victoria to support the development and implementation of policies and practice aimed at supporting the families of adults with a disability and disability service providers to work more effectively together.

The United Nations *Convention on the Rights of Persons with Disabilities* (UNCRPD) and Victoria's *Disability Act 2006* (the Disability Act) both recognise the important role families play in promoting the rights and wellbeing of people with a disability. In spite of this, we have found over six years in operation that many families feel disempowered by the position disability service providers have taken in relation to the family's role in the life of their adult family member with a disability.

We believe that there needs to be an increased focus within the sector on establishing respectful, robust and constructive relationships between service providers and the families of adults with a disability in receipt of disability supports. Further, we believe that doing so is fundamental to the delivery of high-quality disability supports and improved outcomes for people with a disability.

During 2012 and early 2013 DSC conducted a literature search of national and international research related to the relationships between families and disability service providers.<sup>1</sup> While a significant amount of research has been undertaken into working with the families of children with a disability, there appears to have been little research undertaken into relationships between families of adults with a disability and the service providers that support them.

This occasional paper has been developed to elicit feedback from key stakeholders in Victoria's disability sector on the principles and practices that DSC believes can be used by families and disability service providers to work more effectively together in supporting adults with a disability.

1. See the Bibliography at the end of this paper for key articles and reports reviewed.

### Notes to this paper

1. This paper provides strategies specifically for supporting the families of adults with a disability and disability service providers to work more effectively together. These strategies should be implemented while working with people with a disability in ways that respect and support their inherent value, dignity and right to determine, to the best of their ability, decisions affecting their lives.
2. In this paper the term 'families' includes parents, siblings and carers of the person with a disability in receipt of disability supports.

# Part 1:

## What we've learned

Our call to develop policies and practices that support constructive relationships between families and service providers is significantly informed by complaints data collected by our office and the ongoing conversations we've had with people with a disability, their families and service providers.

Five key aspects of our experience have led to this call for change:

- **recognising the role and importance of families and natural supports**
- **patterns in enquiries and complaints made to DSC**
- **characteristics of relationships between families and service providers**
- **differing expectations between families and service providers**
- **people's fear of making a complaint.**

## Recognising the role and importance of families and natural supports

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

The UNCRPD recognises that the family is the natural and fundamental group of society. The UNCRPD also acknowledges the important contribution families make to the full and equal enjoyment of rights experienced by people with a disability.<sup>2</sup> The legislation for Australia's National Disability Insurance Scheme (NDIS) also includes a principle about acknowledging and respecting the role of families, carers and other significant persons in the lives of people with disability.<sup>3</sup>

In Victoria, the important role that families and natural supports play in people's lives has been recognised in both the Disability Act and the *Carers Recognition Act 2012*. Since 1 July 2007 when the Disability Act came into effect, disability service providers have been required to consider, respect and acknowledge the role of families in supporting people with a disability and, where possible, strengthen and build their capacity.<sup>4</sup>

In spite of this, many family members raising issues with DSC have described a sense of disempowerment as a consequence of service providers' perception of their role, particularly with respect to decision making. Some families have recounted stories of being told by service providers that they had little or no role in decisions affecting their family member's life because the person is over 18 years of age. While the family's role may change over time, the notion that their participation in decision making should end when an individual turns 18 reflects an overly simplistic view of how people

progress towards independent decision making, particularly when a person has a cognitive impairment that impacts on their decision making capacity.

***'When I tried to share my knowledge and understanding of [my son] and what I felt was important for him, I often felt dismissed.'***

*Mother of an adult living in a group home*

***'As his family, we want to be recognised as one of the key pillars supporting [our son's] life.'***

*Parent of an adult living in a group home*

While any decision making process should always start with the person with a disability, their family will typically continue throughout their life to be an important source of support with respect to major life decisions (or where the person's cognitive abilities result in them requiring more regular support). DSC believes that quality supports and outcomes are most likely to occur when the family's role is recognised and respected.

2. United Nations *Convention on the Rights of Persons with Disabilities*, opened for signature on 30 March 2007, 993 UNT 3 (entered into force 3 May 2008) Article x. Australia is a signatory, and ratified this convention in 2008.

3. National Disability Insurance Scheme Act 2013, s. 4(12).

4. See Disability Act s. 5 (3) (h),(i), (j), (ja) and (k), and *Carers Recognition Act 2012* s. 7.

## Recognising the role and importance of families and natural supports

The role of families and other natural supports in the life of a person with a disability is recognised in the work currently being undertaken nationally and internationally on the use of circles of support, microboards and supported decision making as critical safeguards for the wellbeing and rights of people with a disability.<sup>5</sup>

In addition, Australian Bureau of Statistics (ABS) data indicates that some people with profound core activity limitations are nine times more likely than the general population to not participate in any activities outside of the home, and they generally experience high levels of social isolation.<sup>6</sup> Given this, encouraging and supporting the involvement of family and other natural supports becomes even more critical in maximising and safeguarding people's rights and wellbeing.

When people with a disability do not have family or other natural supports in their lives, there is the risk that they become wholly reliant on service providers to look out for their day-to-day wellbeing and rights. The Disability Act identifies this as a risk when it requires that:

- **disability services should be designed and administered in a way that ensures that people with a disability have access to advocacy support where necessary to enable adequate decision making about the services they receive (s. 5[3][p])**
- **a particular service provider should not exercise control over all or most aspects of the life of a person with an intellectual disability (s. 6[1][f]).**

There is no question that service providers play an important role in the lives of people with a disability using their services. Equally, it is critical that families and other natural supports are encouraged and supported to be actively involved in that person's life as a means of further safeguarding their wellbeing, as well as bringing meaning and value to their life.

5. See the Bibliography for literature on these approaches.

6. McLachlan, R, Gilfillan, G & Gordon, J 2013. *Deep and Persistent Disadvantage in Australia*, p.140.

## Patterns in enquiries and complaints data

There is a consistent pattern of enquiries and complaints to us and to service providers over the past six years, especially in relation to the source of enquiries and complaints and the type of disability experienced by people on whose behalf complaints are most commonly made.

Tables 1 and 2 below contain aggregate data collected from 2009–10 to 2012–13.

**Table 1:** Sources of enquires and complaints, 2009–10 to 2012–13

Source of complaint	DSC <sup>7</sup>	ACR <sup>8</sup>
Families	49%	54%
People with a disability	24%	24%
Support staff	13%	10%

**Table 2:** People with a disability by type of disability,<sup>9</sup> 2009–10 to 2012–13

Type of disability	DSC	ACR
Intellectual disability	62%	63%
Physical disability	43%	19%
Autism	27%	12%

The majority of complaints to DSC and service providers are about services provided to people with an intellectual disability. It is our experience that many people with an intellectual disability need support, or rely upon others such as family members, to speak up about any concerns about services and supports they are receiving.

In our conversations with families and service providers it is generally acknowledged that, were it not for family members raising complaints on behalf of their family member with a disability, many of these issues would not have been raised and responded to. In addition to having significant implications for the continued improvement of disability supports, this data provides a strong case for families having a say in the delivery of disability supports.

For a more extensive analysis of the complaints data collected by DSC please refer to our annual reports on our website at [www.odsc.vic.gov.au/annual-report](http://www.odsc.vic.gov.au/annual-report).

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

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

9. The total exceeds 100% as many service users have multiple disabilities.

## Characteristics of relationships between families and service providers

While there are many examples of respectful and effective working relationships between families and service providers, DSC has dealt with many instances where service providers have not demonstrated a considered and documented approach to this area of service provision. This can result in practice being dependent upon the attitudes and practices of specific individuals within organisations rather than a planned and considered organisational approach. Many of the responses from disability service providers to questions posed by the Disability Services Commissioner about approaches to working with families<sup>10</sup> included reflections on the need to review and improve the level and nature of the engagement of families with their service.

Based on our experience and analysis of the themes in complaints raised by families, we have identified four forms of engagement that typically occur between families and service providers in the disability sector. We believe that this approach provides an important starting point for service providers seeking to improve the way they work with families. The four categories of engagement are:

- **constructive**
- **ad hoc**
- **marginal**
- **destructive.**<sup>11</sup>

While each type of engagement will arise from a particular set of circumstances and have distinct characteristics, we would expect that there will be times when the characteristics typical of any of these forms of engagement might exist within the one organisation or in their relationships with individual families.

10. Regional visits conducted by the Disability Services Commissioner in 2012–13.

11. These categories were developed by Ron Tiffen drawing on the concept of constructive engagement developed by Bernard Mayer (2009) in *Staying with Conflict: A Strategic Approach to Ongoing Disputes*.

***‘Our relationship with families isn’t strong and there is some confusion about expectations.’***

*Service provider*

***‘I think we are good at it but there is always room for improvement.’***

*Service provider*

***‘We have no direct policy regarding family engagement.’***

*Service provider*

# Characteristics of relationships between families and service providers

## Constructive engagement

Constructive engagement is a planned and considered approach to the working relationship between families and service providers that is based upon a recognition of the important role each party plays in the life of the person with a disability. This form of engagement is reinforced by 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. Agreements would typically cover such areas as:

- the types of supports to be provided
- how supports will be provided
- the type, level and frequency of communication
- how decisions affecting supports will be made and who will be involved
- the level of involvement, roles and responsibilities of the family (particularly where the person with a disability is over 18 years of age)
- how disputes will be addressed.

An individualised agreement is developed, usually through a face-to-face discussion, between the family and a service provider representative who is senior to the staff who will provide direct support to the client.

‘Constructive’ engagement should not be taken to mean that families and service providers will always agree on every aspect of support provision. Nor, depending on the wishes of the person with a disability or their family, will it necessarily result in regular engagement. What it does mean is that there is a respectful, agreed and documented approach about how the parties will work together and how disputes, when they arise, will be addressed.

## Ad hoc engagement

Ad hoc engagement is engagement without a plan, without certainty and without consistency from the service provider. This form of engagement may be experienced positively or negatively by the family and service provider representatives, because it relies upon the attitudes of, and relationships with, individual staff rather than the reliable implementation of a planned and considered approach to working with families by the organisation.

In this type of engagement it is unusual to have a service provider representative senior to the staff providing the direct support meaningfully involved in the engagement. Rather, there is a limited range of contact points between the family and the service provider, and these are most commonly direct support staff, a supervisor, team leader or case manager. The frequency and style of contact may be dominated by only one or two key contacts, and dictated by their individual level of interest or commitment, rather than by a stated expectation of the organisation.

From DSC’s perspective, this form of engagement appears to be the dominant form of engagement between families and service providers in the Victorian disability service system. While the quality of the engagement can vary greatly, the nature of the engagement is inherently fragile and, at times, disempowering. For example, family members often say that the change of a house supervisor in a group home can make a significant difference to how supports are provided. The lack of engagement by senior management can also lead to families believing that managers have little or no understanding of their family member’s support needs.

# Characteristics of relationships between families and service providers

## Marginal engagement

Marginal engagement is the absence of a connection between the family and service provider. Rather than being the result of a considered approach by the service provider, and mutually agreed to by the family (as might occur in constructive engagement), it typically appears to be the result of indifference between the two worlds of service provision and family involvement.

Like ad hoc engagement, the service provider does not have a planned approach to working with families. Unlike ad hoc engagement, however, individual staff do not take it upon themselves to engage meaningfully with families.

There may be some occasional and incidental contact between the family and service provider, but there is no foundation, formal or otherwise, for any real form of working relationship.

## Destructive engagement

Destructive engagement is typically driven by powerful negative emotions between the family and service provider representatives.

In the absence of a mutually agreed and documented approach to how they will work together and how disputes will be addressed, there may be divergent views on the needs of the person with a disability or the quality of service provision. Families and service providers struggle to agree on support plans and how to implement them, and efforts can become focused on the conflict rather than being directed by person centred principles. Tensions arise and people often report significant stress. People lack confidence and trust in one another. There may be allegations and counter allegations that either party is causing poor outcomes for the person with a disability.

Service quality and continuity are at risk in situations of destructive engagement, and resolution can be difficult to achieve. While destructive engagement between service providers and families is less common than other types of engagement, the negative impact on the wellbeing of the person receiving services can be profound. It is therefore critical that principles and strategies are adopted to try to prevent and effectively address this form of engagement.

## Differing expectations between families and service providers

Many issues brought to DSC arise specifically as a result of differing expectations between service providers and families that have not been adequately identified or addressed.

It is common for families and service providers to differ in their expectations of the person with a disability and in their opinion of what's important to and for their wellbeing and safety. For example, they often disagree about finding the balance between the person's independence and right to participate in activities involving a degree of risk and their perceived safety and wellbeing.

In our experience these differences can play out in a number of ways. Families and service providers can adopt different positions on any given issue depending on the circumstances. These differences can be further complicated in a small number of situations where one party views that the other is not acting in ways that maximise the person's overall wellbeing and safety.

While it can be difficult to find resolution, the tensions we observe between families and service providers often arise, not as a result of the issue itself, but due to a failure to discuss, understand and work through each other's concerns.

These conversations can be difficult, since there is often no clear answer as to the best way forward. However, given the issues in dispute often go to the heart of people's quality of life and the supports they receive, families and service providers need to be willing to talk openly and respectfully, over a number of conversations if necessary, about how a person's rights and needs can best be met.

***'I felt frustrated, frightened and powerless when the potentially serious implications of his epilepsy were not acknowledged, and staff did not appreciate the importance of ensuring everyone knew how to effectively treat his seizures.'***

*Parent of a person living in a group home*

## People's fear of making a complaint

The Disability Act clearly states that people have a right to make a complaint about the disability supports they receive. DSC has promoted and supported this right through our message that **'It's OK to complain!'** and our work in the resolution of complaints about disability services.

However, whilst the past six years have seen a steady increase in the number of people who have made complaints, many people with a disability and their families are still afraid to voice their concerns to the service providers they rely on to provide their support.

DSC is aware that the fear of retribution, and loss of valuable services or relationships, result in people not making a complaint and choosing to put up with services that they are not happy with. Many people believe that making a complaint is 'crossing a line in the sand' that will detrimentally and permanently change their relationship with the service provider.

In our view it is difficult to see how people's quality of life and quality of their disability supports can be optimised where they (and, where relevant, their family) are afraid to voice their honestly held opinions about what's working and not working with the services they are receiving.

A challenge for any service provider aiming to genuinely improve people's lives through the delivery of high quality disability supports, is to work out how they can meaningfully empower and enable people to speak up about the supports they are receiving. We believe that constructive working relationships are fundamental to achieving this.

***'I complied because I didn't want [the staff member's] frustration taken out on [my son].'***

*Mother of a person living in a group home*

# Part 2:

## Supporting constructive engagement between families and service providers

Constructive engagement between families of adults with a disability and service providers is most likely to occur when both parties are committed to supporting people to lead a meaningful and valued life that includes active involvement in the range of relationships typical of the community in which they live.

Achieving constructive engagement with families requires service providers to adopt a multilayered and sustained approach that promotes opportunities for families to have input into the disability supports being provided and to play an active role in the life of their family member with a disability.

Throughout the second half of 2012 and early 2013, DSC consulted with a diverse range of stakeholders about establishing constructive engagement between families and service providers. These consultations included conversations with people with a disability, families and service providers. The DSC also established a Family Engagement Reference Group.

From the outset stakeholders agreed that a set of policy principles were required, to give guidance to families and service providers on key aspects of the relationship they shared. The policy principles proposed within this paper were developed in consultation with, and informed by feedback from, a broad range of stakeholders relevant to the disability sector.

The following principles and strategies are based on the premise that disability supports should always place the person with a disability at the centre of those supports and respect their right to be actively involved in determining decisions that affect their lives. Within this context, families and other natural supports are acknowledged as an important safeguard for people who are less able to speak up for themselves and should be recognised as integral (where relevant) to the provision of genuinely high quality person centred supports.

## Policy principles

### Preamble

People's sense of identity, wellbeing and quality of life is strongly shaped by and connected to the relationships they have with family, friends and significant others.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) recognised this when they acknowledged that the family is the natural and fundamental group of society. The UN also acknowledged the important role families have in contributing to the full and equal enjoyment of the rights of people with a disability.

A person with a disability is best supported when there are constructive relationships between the person, their family and their service provider.

Recognition and respect for the role of families in the lives of people with a disability happens best when support providers think and behave in ways that respect the value of all people involved in the person's supports, and where policies and actions support this approach.

When this approach is not in place, recognition of the role of family varies depending on the values and behaviours of individual staff. This can result in people not doing as well.

People with a disability will be supported most effectively where families and service providers commit to the following principles.

## Policy principles

### Principle 1:

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#### **People with a disability have a right to lead a life of their own choosing.**

Families and service providers should acknowledge and respect that people may have different and changing views about the activities and relationships they want to pursue in life.

### Principle 2:

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#### **Relationships are important in people's lives.**

In supporting people with a disability to live rich and fulfilling lives, families and service providers should work in partnership to support each person to pursue a variety of relationships.

### Principle 3:

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#### **'Family' means different things to different people.**

Family relationships are diverse, unique and almost always the most enduring relationships in a person's life. These relationships should be respected and valued.

### Principle 4:

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#### **Both families and service providers contribute to a person's life.**

The knowledge and understanding families and service providers have of people are based on differing relationships and social contexts. Both perspectives are important and should be acknowledged for the contribution they can make.

### Principle 5:

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#### **Differing views should be expressed and respected.**

Where families and service providers have differing views, all people should:

- feel able to express their opinions and concerns in a safe, respectful and supportive environment
- commit to working through their differences in ways that ultimately benefit the person.



Let us  
know what  
you think...

Are there any  
other areas  
you think are  
fundamental to  
the relationship  
between families  
and service  
providers that the  
principles should  
touch on?

# Strategies for service providers to embed principles into practice

DSC believes that the policy principles proposed in this paper are an important foundation for achieving constructive engagement between the families of adults with a disability and disability service providers.

For the principles to be effective they need to be integral to the standard practices of the organisation. They need to be actively embedded into the:

- **organisational culture and structures** – the thinking, attitudes and formal structures that sit behind the organisation’s day-to-day practice
- **delivery of supports** – the conversations, processes and practice that support the development, implementation and delivery of the disability supports provided.

The strategies proposed in this paper are based on our experience in dealing with more than 3,700 enquiries and complaints about the delivery of disability supports in Victoria, and on feedback reported to us from disability service providers through the Annual Complaints Report (ACR) process.

The strategies are designed to address two particular areas that commonly feature in the matters brought to DSC:

- a lack of a planned approach by many disability service providers to working with families<sup>12</sup>
- the misunderstandings that occur, often in the early stages of the working relationship, about what supports will be provided, how they will be provided and at what cost.

The strategies outlined in the following sections do not address approaches to resolving disputes or ‘destructive engagement’ between families and disability service providers. They are intended to support a proactive approach to achieving constructive engagement between families and disability service providers. DSC continues to develop training and resources for effective complaints resolution, and work is underway on specific approaches for dealing with ‘difficult conversations’ and ‘high conflict behaviours’.

12. See discussion in Part 1, ‘Characteristics of relationships between families and service providers’.

# Strategies for organisational culture and structures

The following strategies reflect DSC's belief that disability service providers need to embed as an integral part of their organisational culture an expectation that, along with people with a disability, families will be consulted and involved in the development, implementation and review of organisational arrangements and services. Where relevant, DSC has identified 'key considerations' that organisations should take into account when considering the adoption of particular strategies.

## Organisational values

Principles:  
1, 2, 3 & 4

### Strategies:

- The organisation's values clearly acknowledge the value of, and state a commitment to, supporting people with a disability to determine and pursue strong and meaningful social networks, which would typically include their family.
- The organisational values recognise the important role families and other natural supports have in the lives of people with a disability, particularly for those who have a limited capacity to speak up for themselves.

## Representation on the board of management

Principles:  
3 & 4

### Key considerations:

Based on complaints data collected by both DSC and Victorian disability service providers, approximately 50 per cent of all complaints received are made by family members. In consultations DSC has undertaken with the sector it is widely acknowledged that most of these complaints would have gone unreported had it not been for families advocating on behalf of their family member with a disability. On this basis alone it is evident that families represent an important voice that should be heard at board level.

While no one person will necessarily represent the views of the entire stakeholder group they are a part of, they can provide insight into how the rest of that stakeholder group might perceive or react to any given issue or proposal that is put before the board.

### Strategies:

- The organisation's constitution ensures that the perspective of family members of people in receipt of services is represented in the organisation's governance structure.
- The organisation considers having more than one representative of family members in its governance structure to provide opportunities for peer support.

# Strategies for organisational culture and structures

## Working with families – policy and procedure

Principles:  
1, 2, 3 & 4

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### Key considerations:

As evidenced in matters brought to DSC, the absence of a policy for working with families<sup>13</sup> can result in a lack of clarity for staff about the organisation's expectations in this area. This can result in inconsistency in the level of support and communication experienced by families. DSC's experience suggests that this can have a detrimental impact on the supports provided to the person with a disability.

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### Strategies:

- The organisation has a clearly documented approach to working with the families of the people with a disability that it supports that is in line with its organisational values.
  - The approach is developed in consultation with people with a disability who are supported by the organisation, and with their families.
  - In addition to reinforcing the importance of people's social networks and relationship with family, the policy and procedure includes (but is not limited to):
    - ◆ the organisation's position on the areas identified by the principles
    - ◆ the need to be clear on and respect the nature of the relationship that exists between the person with a disability and their family
    - ◆ the organisation's role in actively supporting the person's relationship with their family
    - ◆ the approach that will be adopted by the organisation to families who have disengaged from their family member with a disability (taking into account that person's views)
    - ◆ the roles and responsibilities of families in the day-to-day support of their family member with a disability
    - ◆ the role of family in decision making
    - ◆ families' access to information about their family member with a disability
    - ◆ how agreements made with families in relation to the delivery of support will be documented and reviewed.
- 

13. Having a specific policy on working with families was a requirement of disability standards in the *Quality Framework for Disability Services in Victoria 2007*, 8.11.10. While the *Department of Human Services Standards* do not include this level of detail, DSC's view is that such a policy is still required to demonstrate how disability service providers uphold the principles relating to the role of families in s. 5 (3) (h), (i), (j), (ja) and (k) of the Disability Act.

# Strategies for organisational culture and structures

## Use of terminology

Principles:  
3 & 4

### Key considerations:

In the matters dealt with by DSC, communication is almost always raised as an issue of concern – in terms of the tone and frequency and, in some cases, the terminology used by service providers.

Like all sectors, the disability sector adopts and uses particular terms and phrases that become part of the common ‘language’. This language changes over time, to reflect emerging theories and approaches to service delivery that are perceived as more progressive, or to succinctly express what are often quite complex issues.

DSC has identified two terms that families can find particularly offensive or distressing.

### 1. When service providers refer to themselves as the **primary carer** of the person with a disability

Disability service providers are responsible for coordinating and providing the daily living supports an individual requires receiving services. In spite of this it would be rare for a service provider to be perceived as more important, or as having a more significant long-term role in decision making, in that person’s life than the person’s family.

Victoria’s *Guardianship and Administration Act* 1986 defines a primary carer as ‘any person who is primarily responsible for providing support or care to a person’<sup>14</sup> with the following qualifications:

- that a person is only to be regarded as ‘having the care’ of a person where they provide or arrange domestic services and support ‘other than wholly or substantially on a commercial basis’ (s. 37 [2])
- a person who is cared for in an ‘institution’ (including a community residential unit), is ‘not, by reason only of that fact, to be regarded as being in the care of that other person and remains in the care of the person in whose care he or she was immediately before being cared for in that institution’ (s. 37 [3]).

In light of the above DSC is not sure what is to be gained from service providers describing themselves as a person’s primary carer. As highlighted in Principle 4 of the proposed policy principles, both families and service providers play an important role in people’s lives; families through their relationship to and long-term involvement in decision making for their family member and service providers through their role in providing daily living support. Both should be recognised for their respective roles.

14. Victorian *Guardianship and Administration Act* 1986, s. 3

# Strategies for organisational culture and structures

## Use of terminology

Principles:  
3 & 4

*continued*

### 2. When families are referred to as having **relinquished** their family member with a disability.

For a variety of often complex and extremely personal reasons, a small number of families have little or no contact with their family member with a disability.

The Victorian Equal Opportunity and Human Rights Commission notes in its report *Desperate Measures*<sup>15</sup> that, in the vast majority of cases, families place their family member with a disability into care because they feel they are no longer able to provide for the person's day-to-day care needs, not because they want to 'give up on', end or significantly reduce their relationship with their family member.

#### **Strategy:**

Service providers consider carefully the language used to describe situations that are often complex and intensely personal. In particular, service providers refrain from using the terms 'primary carer' (when referring to their role in a person's life) and 'relinquish', and instead use language that more accurately and sensitively describes the situation at hand.

## Participation in strategic planning and advisory groups

Principles:  
3 & 4

#### **Strategies:**

- Families are actively encouraged to participate in the range of activities that occur within organisations to influence and shape how supports are delivered.
- Service providers ensure that activities and forums such as strategic planning, finance subcommittees, quality advisory groups and human rights committees include representatives of the families of people supported by the organisation. In some cases, for example a finance subcommittee, it is reasonable and necessary that family members possess the relevant skills and expertise.

15. Victorian Equal Opportunity and Human Rights Commission 2012.  
*Desperate Measures: The relinquishment of children with a disability into state care in Victoria.*

# Strategies for organisational culture and structures

## Human resources

Principles:  
3 & 4

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### Position descriptions

#### Strategy:

The service provider's commitment to supporting the development and maintenance of people's social networks, including their relationship with their family, is strongly reflected in the position descriptions of all staff, in particular those staff likely to have direct involvement with, or influence on, the delivery of supports.

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### Interview panels

#### Strategy:

Families of people supported by the organisation are represented on interview panels when recruiting staff who are likely to have direct involvement with, or influence on, the delivery of supports.

- When interviewing for group-based support staff, people with a disability and family members have equal say with other members of the interview panel.
  - When interviewing for staff to provide individualised supports, the person being supported, with the help of their family where necessary, has final say over who provides their supports.
- 

### Interview questions and process

#### Strategies:

- Family members have input into the development of interview questions. This input could be provided, for example, through representation on interview panels or through a broader consultation process.
  - An alternative or addition to the above is to have job candidates meet and spend time with the people being supported and their families. Staff observations of how the candidate relates to the people they meet with, and feedback from the other people involved, can contribute to the decision making process.
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### Referee checks

#### Strategy:

Referee checks include a focus on the candidate's commitment to and skills in relating to and supporting people with a disability and their families.

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### Staff induction and orientation

#### Strategy:

Staff induction and orientation reinforce the organisation's values and commitment to supporting people's social networks and relationship with their family. There are a variety of ways that this can be achieved – by reiterating the organisation's values, through discussing case examples or digital stories, or by having a family member speak to participating staff.

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### Staff supervision and performance appraisal

#### Strategy:

In line with the organisation's values, and as a core element of the supports being provided, people's social networks and relationship with family are a standard area of staff supervision and appraisal.

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# Strategies for organisational culture and structures

## General consultation and feedback

Principles:  
3, 4 & 5

### Key considerations:

As outlined in DSC's *Good Practice Guide and Self Audit Tool* and the *Everything You Wanted to Know about Complaints...* booklet,<sup>16</sup> delivering high quality person centred supports is about enabling people with a disability to speak up, so that action can be taken to build on what is working and address what may not be working.

Service providers have a responsibility to:

- actively identify the ways they will seek feedback from people with a disability receiving supports
- actively seek feedback from the families of the people they support, particularly where the person with a disability has a limited ability to advocate for themselves.

It is important to let stakeholders know what feedback has been received and how it is being acted upon. Failing to do so can:

- create a perception of a lack of transparency; that the organisation is 'hiding' what may have been less than positive feedback
- diminish the likelihood that stakeholders will bother making the effort to provide feedback in the future
- undermine stakeholders' perception of the value the organisation places on their opinion.

### Strategies:

Feedback is sought from people in receipt of supports and their families in a variety of ways both formal and informal including:

- customer satisfaction surveys (administered 'in house' or by an independent organisation)
- events such as an afternoon tea which provide opportunities for informal discussion and feedback on the organisation's performance
- regular reminders via a range of communication mediums about the importance of feedback to improving service quality, and about people's right to speak up, and where necessary complain, about the services being provided.
- Information is provided by the organisation to people with a disability, their families and staff outlining the feedback received and how it is being acted upon.

16. See Disability Services Commissioner, *Good practice guide and self audit tool: Developing an effective person centred complaints management culture and system*. Second Edition 2013, p6 and *Everything you wanted to know about complaints... Tips for service providers on successfully resolving complaints and seeing the opportunities for improvement*. 2013, p2.

# Strategies for organisational culture and structures

## Reinforcing people's right to speak up or make a complaint

Principles:  
4 & 5

### Key considerations:

- Genuinely person centred supports can only exist where people feel confident and safe to speak up about what's working and not working with their supports.
- Many people with a disability and their families are reluctant to make a complaint for fear of retribution or loss of service. DSC believes that, in line with the principles and requirements of the Disability Act,<sup>17</sup> service providers have a responsibility to proactively work to reassure people that **It's OK to complain!**

### Strategies:

- Organisations review their complaints culture and processes in line with DSC's *Good Practice Guide and Self Audit Tool* and the *Everything you wanted to know about complaints...* booklet.
- Service providers encourage people with a disability and their families to speak up including:
  - ◆ reminding people at regular intervals through newsletters, websites and other forums of their right to speak up or make a complaint
  - ◆ ensuring that all staff understand the critical role families have in relation to speaking on behalf of their family member with a disability, particularly where the person has difficulty advocating effectively for themselves
  - ◆ ensuring that all staff understand the value and importance of complaints as an expression of people's right to speak up
  - ◆ ensuring that staff know how to respond effectively when people make a complaint
  - ◆ informing stakeholders about improvements and changes made as a result of complaints received (respecting confidentiality requirements).



Let us  
know what  
you think...

**Are there any other critical organisational practices or structures you think should reflect an organisation's approach to working with families?**

17. Part 2 and Part 6 Divisions 5 and 6 of the Disability Act.

## Strategies for the delivery of supports

Many of the issues brought to DSC have arisen as a result of inadequate discussion between the person being supported, their family, the service provider and others facilitating the development and purchase of supports, about issues directly relevant to the implementation of the supports being provided.

DSC proposes a series of key considerations and strategies, outlined in the following pages, to assist organisations to embed the principles for constructive engagement into the delivery of supports. These key considerations and strategies should be discussed, considered and documented at each stage of engagement:

1. in the lead-up to choosing the support provider<sup>18</sup>
2. during the development and documentation of the supports to be provided
3. at regular intervals as required after provision of supports begins.

While every effort should be made to maximise the involvement in decision making of the person who is to receive the supports, where they have a limited ability to contribute fully to the discussion service providers should also consult as appropriate with the person's family or other identified natural support networks.

18. While it may seem that less detail is required at this stage of the process, any assumptions made about the exact nature of the supports to be provided can potentially lead to misunderstandings and conflict about the subsequent provision of supports.

# Strategies for the delivery of supports

## Clarification of the supports sought and available from the service provider

Principles:  
1, 2, 3 & 4

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### Key considerations:

Many issues brought to DSC are a result of differing expectations of service providers and families that have not been adequately identified or addressed. Many of these issues can be prevented if service providers adopt strategies to address these expectations in the initial discussions and planning processes for the development of supports.

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### Strategies:

- When involving families in the planning and development of supports, discussions are initiated about what is important to and for the person receiving the supports. The planning and documentation of supports captures as much detail as possible about:
    - ◆ the person's high-level goals and aspirations, including their wants and needs in relation to maintaining and developing a social network (including the relationship with their family)
    - ◆ details about how their daily living supports and routines are to be provided. This is particularly critical to ensuring the consistency and quality of the supports to be provided in situations where there are likely to be multiple staff involved in the delivery of those supports. Areas to be considered include (but are not limited to)
      - the person's preferred daily routines (including how they can be supported to maximise their independence)
      - health-related supports (diet, medication, fitness, bowel care, continence aids, medical and dental reviews and other areas as relevant)
      - the range of social, cultural, spiritual and work-related activities and relationships the person is to be encouraged and supported to participate in.
  - The planning process recognises that people sometimes demonstrate different skills, attitudes and interests when with their family than with paid support staff. Families and service providers acknowledge and discuss these differences as they occur, and incorporate them into the person's planning and support.
  - The family and service provider discuss how plans will be amended, both formally and informally, in line with the person's changing needs and preferences and how changes will be communicated to all concerned.
  - The service provider clearly outlines their capacity to provide the supports required in the way they are required and preferred, including:
    - ◆ their knowledge of and experience in the specific supports sought
    - ◆ any impact the provision of supports might have on their obligations to the other people they support
    - ◆ their responsibility to meet the requirements and principles of the Disability Act, their duty of care and the delivery of the supports they provide.
  - Where the organisation is unable to provide all aspects of the support required in the preferred manner, this is identified, discussed and documented to inform subsequent support relationships.
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# Strategies for the delivery of supports

## Roles and responsibilities of the family and service provider

Principles:  
1, 2, 3, 4, & 5

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### Key considerations:

A common feature of many matters brought to DSC is a lack of clarity and agreement between families and disability service providers about their respective roles and responsibilities in relation to the supports being provided. Clarifying these areas improves the quality and consistency of the supports provided and reduces the likelihood of future misunderstandings and disputes.

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### Strategies:

The initial planning and development of supports includes clarification of respective roles and responsibilities of the family and disability service provider in relation to the delivery of the supports to be provided. Discussions cover areas such as:

- the willingness of both the family and service provider to commit to the principles as the basis of their working relationship
  - communication (see specific strategies below)
  - decision making (see specific strategies below)
  - the degree to which the family wishes to be involved in their family member's supports
  - balancing the family's desire to be involved and the service provider's legislative obligation to promote the person's independence and dignity of risk, particularly in relation to decision making
  - the service provider's legal and duty of care responsibilities relating to both the person being supported and to the management and direction of staff – these may impact on the family's involvement in specific aspects of the person's support.
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## Communication

Principles:  
3 & 4

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### Strategies:

- Discussions take place, and are documented, to clarify each other's expectations in relation to communication.
  - Where possible, the parties reach a clear and common understanding about the wishes and preferences of the person with a disability in relation to the level of access family and other natural supports have to information and communication about different aspects of their life.
  - Where the person with a disability has limited ability to indicate their wishes and preferences about the role other people in their lives will play in communicating with the service provider, discussions aim to clarify and reach agreement about:
    - ◆ the people who will have primary responsibility for communication (which may vary in relation to specific issues)
    - ◆ the types of information to be exchanged
    - ◆ needs, preferences and expectations in relation to the frequency, detail, timeliness and mode of communication
    - ◆ procedures for emergency situations.
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# Strategies for the delivery of supports

## Privacy and information sharing

Principles:  
1, 2, 3 & 4

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### Key considerations:

Issues relating to sharing, or restricting access to, information about their family member have been a common source of tension between families and service providers in complaints dealt with by DSC.

Legislation that relates to access and disclosure of personal and health information in disability services includes:

- *Freedom of Information Act 1982*
- *Health Records Act 2001*
- *Information Privacy Act 2000*

DSC has reviewed the application of these legislative provisions to the access and disclosure of personal and health information in the disability sector. The purpose of these provisions are to facilitate individuals' access to information and documentation held by certain organisations and agencies. While there are some important exceptions to this right that may limit the ability of organisations to share information, the underlying intent of the legislation is to promote a culture of open communication that facilitates fast and efficient access to information. This should be achieved through informal processes where possible.

The only situations in which a service provider must not disclose information are:

- when it is against the wishes of the person the information relates to
- when doing so poses a serious threat to the life of the person the information relates to
- when the information was provided in confidence.

Other than the above restrictions, legislation confers discretion on organisations in deciding whether to share certain types of information or in certain situations.

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### Strategies:

- The organisation states its position, in accessible language, on:
    - ◆ sharing information about an individual (including its obligations to any other people who might be named in information being sought by the person or their family)
    - ◆ the importance of families sharing all information relevant to the service provider's ability to optimise the support they provide to the person and to enable them to meet their duty of care.
  - The organisation's approach to sharing information about people with limited or no capacity to indicate their preferences in this area, reflects the organisation's stated values and the principles relating to the role and importance of family in people's lives.
  - Any questions or issues about sharing information are openly discussed and clarified by all relevant parties at the beginning of any support arrangement.
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# Strategies for the delivery of supports

## Decision making

Principles:  
1, 3 & 4

### Strategies:

Discussions take place to clarify people's expectations in relation to how decisions affecting the person's life will be made. This includes but is not limited to clarification, negotiation and agreement in the following areas:

- the degree to which the person with a disability is capable, and can be supported, to make informed decisions about various aspects of their own life. In line with the Disability Act, the exercise of control and choice by the person with a disability is encouraged and supported as much as possible, recognising the existing and potential capacity of the individual
- where it is agreed that the person with a disability requires support to make decisions about particular aspects of their life;
  - ◆ the decisions the service provider can make on behalf of the person without consulting with their family (such as day-to-day decisions)
  - ◆ the decisions the person's family are to be consulted about
  - ◆ the decisions the family may need to make as guardian under the *Guardianship and Administration Act 1986*.<sup>19</sup>
  - ◆ which family members are the primary contact for decisions (including whether this varies depending on the issue at hand)
  - ◆ who is to be contacted, and when, in emergency situations (and what is expected of the service provider if they cannot reach the person).

### Note:

Article 12 of the UNCRPD requires recognition of the right of people with a disability to exercise their legal capacity on an equal basis with others in all aspects of their life, and their right to be supported to do so.<sup>20</sup> Proposed reforms to the *Victorian Guardianship and Administration Act 1986* include provisions for supported decision making which may play a key role in future approaches to decision making if new legislation is introduced.<sup>21</sup>

19. Part 4 and Part 4A of the *Guardianship and Administration Act 1986*

20. United Nations *Convention on the Rights of Persons with Disabilities*, Article 12, Clauses 2, 3 and 4

21. Victorian Law Reform Commission 2012. *Guardianship. Final Report 24*

# Strategies for the delivery of supports

## Families who have disengaged from their family member with a disability

Principles:  
1, 2, 3 & 4

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### Key considerations:

- Families disengage from their family member with a disability for a range of reasons, including by personal choice, familial or cultural pressures or advice from professionals about what is in people's best interests at a point in time.
- Service providers are rarely, if ever, privy to the reasons for a family's decision, and they need to respect the diversity of relationships that can occur in families. It is inappropriate for service providers and their staff to 'judge' families in this situation.

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### Strategies:

While respecting both the person's and family's decision, particularly when a person is new to a service, the organisation sensitively and respectfully clarifies:

- how the person with a disability feels about the loss of contact with their family, gauge any interest they may have in re-engaging with them, and support them to cope with these issues.
  - the family's desires in relation to contact with their family member
  - the family's preferences or priorities for how the person is supported, even though they do not wish to play an active part in the person's life
  - whether there are any circumstances or ways in which the family wishes to maintain contact with their family member
  - whether the family is open to being contacted at agreed intervals to update them on their family member and to re-confirm their preferences in relation to contact with their family member.
-

# Strategies for the delivery of supports

## When disagreements arise

Principles:  
4 & 5

### Key considerations:

- Given the highly individualised and personal nature of disability supports, and the challenges and limitations often faced by service providers, there will be times when the person with a disability, their family and the disability service provider might disagree about how supports are best provided.
- DSC's view is that it is best to discuss and agree on how such disagreements will be handled at the beginning of the support arrangement, rather than attempting to do this when actually involved in a dispute. Principle 5 of the policy principles provides a foundation for these discussions.

### Strategies:

Discussions take place at the start of the support arrangement. It is acknowledged that each party has a significant and important contribution to make to the person's supports. It is also acknowledged that disagreements may arise regarding what's in the best interests of the person and/or the details of supports to be provided. Both the family and service provider honestly and openly discuss and seek to reach agreement on:

- what they expect of one another in relation to both behaviour and communication when disagreements arise
- the point at which either party may choose to temporarily cease communicating with the other party and how this will be communicated at the time
- how it will be communicated when either party believes the other party has not adhered to the intent or detail of agreements made about how disagreements will be dealt with
- when advice and assistance from an independent third party is required to assist in the resolution of a disagreement.

Let us  
know what  
you think...

**Are there any other areas critical to the delivery of supports that you think should reflect an organisation's approach to working with families?**

## Strategies and resources for families

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.

DSC has developed the following set of questions as a starting point for the development of strategies and resources for families choosing or working with a disability provider. These questions could also be used as a resource for disability service providers to review their current practices in engaging, working with and seeking feedback from families.

It is envisaged that this material will form part of a stand-alone resource for families of adults with a disability to be developed by DSC.

### Questions to consider when choosing and working with a disability service provider

Good communication and relationships between the person with a disability accessing supports, their family and the service provider can play a critical role in promoting the best possible service outcomes and experiences.

Many issues and complaints can be avoided or easily dealt with if time is taken to have conversations when choosing and beginning to work with a service provider about the respective roles your family and the service provider will play in your family member's supports.

Families can vary in relation to the level of input they wish to have into the disability supports their family member is receiving. The following prompts and questions are intended as a guide to help you evaluate service providers on their commitment to working with families and whether their approach aligns with your own views about the level of input you would like to have.

As a starting point, two key questions that may assist you to clarify what's most important to you in a relationship with a service provider are:

- **When the relationship with your family member's service provider is working well, what would you anticipate it will look and feel like?**
- **What would be some of the signs that the relationship is not working well?**

Keeping the above in mind, the following are further questions to consider when:

- you are choosing a service provider
- your family member is starting to receive a service
- making agreements with the service provider about communication and how decisions affecting your family member will be made
- you have concerns about the services being provided to your family member.

# Strategies and resources for families

## Choosing a service provider

- 1** Have you thought about how involved you want to be with the service, and have you talked to the service provider about this?
- 2** How, and about what sorts of issues, would you like to be communicated with and how frequently would you like the communication to occur?
- 3** What is the service provider's policy and approach to working with families? Is it documented? Does this approach fit with your expectations?
- 4** Does the service provider invite family members to assist in developing, implementing and reviewing information developed by the organisation including policies and procedures?
- 5** Do you think you will feel welcome, involved and included in the provision of the support and assistance for your family member?
- 6** What opportunities exist for families to be involved in the organisation and/or their family member's supports, for example, board of management, advisory groups, feedback surveys, staff recruitment and so on?
- 7** What is the service provider's approach to person centred planning and will you have the opportunity to be involved in the development of a plan for your family member?
- 8** Do you think you would feel comfortable raising and discussing any issues or differences in views that may arise between you and the service provider? Is information about the service provider's approach to receiving feedback and complaints clear and accessible?

## Strategies and resources for families

### When your family member starts to receive a service

- 1** Have you talked to the service provider about your expectations of how supports will be provided to your family member so as to reduce the potential for misunderstandings?
- 2** Has the service provider talked to you about your family member's rights under the *Disability Act* 2006 and the quality standards for the provision of disability services?
- 3** Do you know about and understand the service provider's process for planning supports for your family member, such as how and when will you be involved in developing, reviewing and updating a plan?
- 4** Are you comfortable with the possibility that the service provider may get to know your family member differently, and see different skills and attributes in them, than you do?
- 5** Has the service provider given you sufficient and clear information about the supports to be provided, the skills and experience management and staff have in delivering those supports and any relevant conditions (for example, fees, complaints process and so on)?

# Strategies and resources for families

## Communication and decision making

- 1** Have you talked with the service provider about your respective views on the capacity of your family member to make their own decisions about various aspects of their life?
- 2** Have you agreed on how communication will work best for you and the service provider (such as how, when, by whom and so on) in order to achieve the best outcomes for your family member?
- 3** Have you agreed on what decisions the service provider is able to make in relation to your family member's support without your involvement, what decisions they need to consult you about and what decisions you would expect to make?
- 4** Has the service provider discussed with you the circumstances in which they will and will not be able to share information with you about your family member?
- 5** Have you agreed about how staff should raise concerns with you if they are worried or upset by something in relation to your family member?
- 6** Are you clear on the best way to raise any issues or concerns you may have with staff?
- 7** Do you know the names of the staff directly involved in the care and support of your family member and the manager of the service area they are supported by?
- 8** Are you clear and comfortable about how differences between yourself and the service provider will be addressed?

### When you have concerns about the service being provided to your family member

**1** Do you know that it's okay to speak up, question, and if necessary make a complaint, if you have concerns about a service being provided to your family member and that making a complaint can make things better?

**2** Did you know that it's against the law for people to be disadvantaged for making a complaint?

**3** Do you feel welcome, involved and included in the provision of the support and assistance to your family member? If not, is there someone in the service you can raise this concern with in the first instance?

**4** Do you know how to raise any issues or concerns you may have with staff or the service? If you are not sure, can you ask for information on the service provider's complaints and feedback policy?

**5** Do you feel that you can regularly and easily communicate with staff and the service and vice versa? Could your concerns be addressed if communication was improved?

**6** Are there differences in opinions about what is important to and for your family member? If so, could asking for a review of your family member's support plan, or seeking the assistance of an advocate, be a way of sorting out these differences?

**7** When you raise concerns do you focus on what happened, how you felt and what outcome or improvement you would like to see for your family member?

**8** Do staff respond in an open and welcoming way if you raise a concern or do they become upset and defensive?

**9** Have you thought about the way in which you raise issues with staff and the organisation and whether this is helping to create the type of relationship that will best serve the interests of your family member?

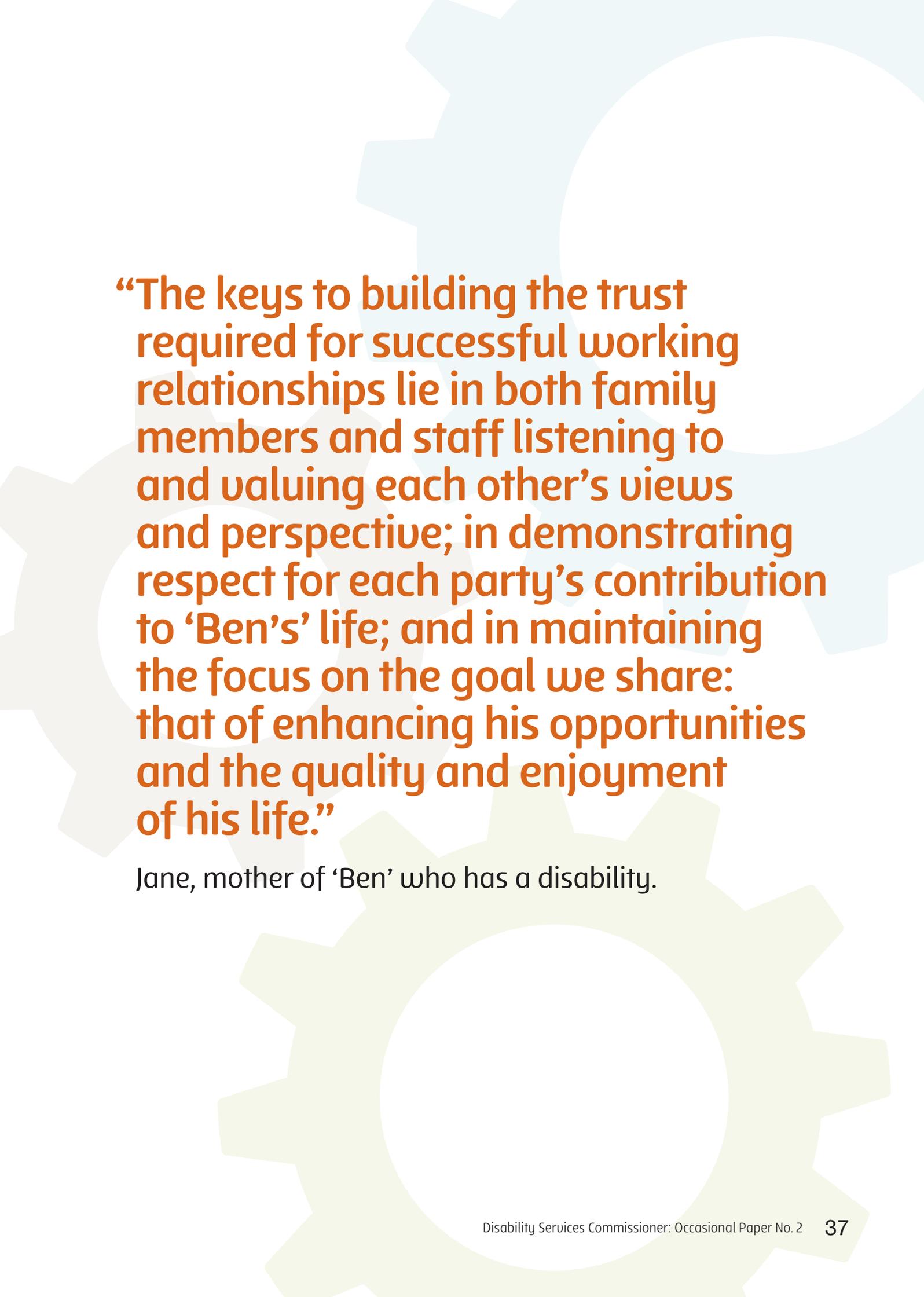
**10** Has the service provider made you aware of your right to have an advocate assist you to raise your concerns?

**11** Has the service provider made you aware of your right to contact the Disability Services Commissioner to assist in resolving any concerns you have about the service your family member is receiving?



Let us know what you think...

**Are there any other critical areas you think families should be prompted to think about when choosing or working with a service provider?**



**“The keys to building the trust required for successful working relationships lie in both family members and staff listening to and valuing each other’s views and perspective; in demonstrating respect for each party’s contribution to ‘Ben’s’ life; and in maintaining the focus on the goal we share: that of enhancing his opportunities and the quality and enjoyment of his life.”**

Jane, mother of ‘Ben’ who has a disability.

# Appendix A: Mandate and functions of the Disability Services Commissioner

Victoria's Disability Act specifies functions and powers for DSC that require us to:

- review and identify causes of complaints and suggest ways of removing and minimising those causes (s. 16 [b])
- consider ways of improving disability services complaints systems (s. 16 [h])
- provide training about the prevention and resolution of complaints relating to disability services (s. 16 [o])
- conduct research into complaints relating to disability services and mechanisms for resolving complaints relating to disability services (s. 16 [p]).

The Disability Act also provides that, in facilitating the resolution of complaints, we seek to improve service delivery. We do this through a person centred and rights-based framework that aims to uphold the principles of the Disability Act in the provision of disability services in Victoria.

Information and experiences that inform DSC's practice and knowledge are drawn from the following areas of our operation:

- complaints and enquiries to DSC
- enhancing sector capacity
- sector monitoring and analysis of complaints
- consultations and engagement with other jurisdictions
- consultations and visits to disability service providers.

## **Complaints and enquiries to DSC**

DSC has dealt with over 3,700 enquiries and complaints since the office opened in July 2007. The Disability Act provides that any person may make a complaint to DSC. DSC's jurisdiction includes complaints about the provision of services and handling of complaints by registered, funded and contracted disability service providers, including the Department of Human Services. Since July 2013, this includes disability services funded through the NDIS in the Barwon trial site.

## **Enhancing sector capacity**

DSC works directly with people receiving support from, or working in, the disability sector. DSC raises awareness about people's right to complain and provides advice on improving the handling of complaints. In doing this DSC staff consult with people with a disability and their family members, service providers, parent associations, members of the community and advocates. DSC representatives also participate in forums and conferences about the ongoing development of the disability sector.

# Appendix A: Mandate and functions of the Disability Services Commissioner

## **Sector monitoring and analysis of complaints**

The Disability Act requires all registered, funded and contracted disability services in Victoria to report annually to DSC on the number, type and outcome of complaints received. Through this Annual Complaints Reporting (ACR) process we have collected and analysed data on over 8,400 complaints dealt with by service providers.

## **Consultations and visits to other jurisdictions**

In 2010 the Commissioner and staff from DSC travelled to all states and territories of Australia to speak to agencies that deal with complaints about disability services and related jurisdictions. These consultations highlighted that the need to strengthen the relationships between families and service providers is not isolated to Victoria or to the disability sector. There is a call from many quarters for attention to the role of families in the provision of personal and daily living supports.

## **Consultations and visits to disability service providers**

In 2012–13 the Commissioner and staff visited over 250 Victorian disability service providers to further inform our understanding of existing practices in the sector, and to talk about their thoughts on, and approach to, working with families. While some service providers felt they had a good working relationship with families, others acknowledged this was an area that needed improvement.

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Disability Services Commissioner is an independent voice promoting rights and resolving complaints about disability services in Victoria.



### **Disability Services Commissioner**

Level 30, 570 Bourke Street, Melbourne Victoria 3000

Office enquiries: 1300 728 187 (local call)

Enquiries and complaints: 1800 677 342 (free call from landlines)

TTY: 1300 726 563

Fax: (03) 8608 5765

Twitter: @ODSCVictoria

Facebook: [www.facebook.com/DSCVic](http://www.facebook.com/DSCVic)

Skype: ODSC Victoria

[www.odsc.vic.gov.au](http://www.odsc.vic.gov.au)

