

# THE UNCOUNTED COSTS: CHOICE AND CONTROL FOR PEOPLE WITH BEHAVIOURS OF CONCERN

Implementing the National Disability Insurance Scheme

Social Action and Research Centre

Anglicare Tasmania

Optia

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The research findings, conclusions and recommendations of this report are those of Anglicare and Optia and should not be attributed to any members of the Research Reference Group. Any errors in the report are the responsibility of the author alone.

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# CONTENTS

<b>Executive Summary</b> .....	<b>1</b>
<b>Recommendations</b> .....	<b>2</b>
<b>1 Introduction</b> .....	<b>3</b>
1.1 What are behaviours of concern?.....	3
1.2 Choice and control in the NDIS.....	4
1.3 Anglicare and Optia.....	5
1.4 Aims of the research.....	6
1.5 Research methods.....	6
1.6 Limitations of the research.....	7
<b>2 People with Behaviours of Concern: Nine Case Studies</b> .....	<b>8</b>
2.1 Behaviours of concern.....	8
2.2 Developing case studies.....	8
2.2.1 Very high intensity.....	10
2.2.2 High intensity.....	12
2.2.3 Stabilised/cyclical.....	14
<b>3 Working with Behaviours of Concern</b> .....	<b>16</b>
3.1 Establishing and maintaining a support team.....	16
3.2 Care coordination.....	19
3.3 Working with families.....	20
3.4 Managing behaviours and training.....	21
3.5 Managing the impact of behaviours of concern on staff, other participants, property and vehicles.....	23
3.6 'No shows' and lack of engagement.....	25
3.7 Managing risk to the organisation.....	26
3.8 Transitioning to the NDIS – choice and control for people with behaviours of concern.....	27
3.9 Experiences of community service organisations in other jurisdictions.....	30
3.10 In summary.....	31
<b>4 Costing the Uncounted Costs</b> .....	<b>32</b>
4.1 Reviewing NDIA prices.....	32
4.2 Case studies and uncounted costs.....	33
4.3 In summary.....	35
<b>5 Conclusions and Recommendations</b> .....	<b>37</b>
5.1 Conclusions.....	37
5.2 What is required?.....	37
5.3 Recommendations.....	38
<b>References</b> .....	<b>40</b>
<b>Appendix 1: Methodology for Costing Fictional Case Studies</b> .....	<b>41</b>
<b>Index of Tables</b>	
Table 1 Number of participants with behaviours of concern.....	9
Table 2 Efficient Price (in 2014) – Assistance self-care and community support.....	33
Table 3 Case Studies: Annual Uncounted Support Costs.....	34

# EXECUTIVE SUMMARY

This research investigates how far the National Disability Insurance Scheme (NDIS) and the development of a disability support market can offer choice and control to people with behaviours of concern. For the purposes of the research this group is defined as ‘people whose behaviour generates a series of indirect or transaction costs (unaccounted costs) beyond direct support costs which are not included in the current standard price list for the NDIS’. Using the experiences of two provider organisations in Tasmania – Anglicare and Optia – the research examined in detail what is involved in providing support for people with behaviours of concern and how this experience can be considered within the NDIS.

The research found:

- The number of people with behaviours of concern is small in any given location. Some people have behaviours of concern all the time but many more move in and out of this group depending on changes in their circumstances and how well services are meeting their needs. They may require intensive support over a long period of time and it may be months or years before some are successfully supported to achieve fully inclusive outcomes. In Tasmania it is estimated that approximately 120 people will present with a history of severe behaviours of concern in any one year (McClellan 2012). Anglicare and Optia between them support approximately 53 people who would fall into this category.
- People described as having behaviours of concern are very diverse. They may include people with co-morbidity, cognitive/communication limitations, acquired brain injury, intellectual disability or autism. They may put themselves or others at risk, demonstrate verbal or physical aggression, damage property and vehicles, have self-injurious behaviour or have complex or challenging families. Their needs can be unpredictable and their capacity to indicate their preferences limited. The research examined the range and diversity of these characteristics and their impact on support services through nine case studies.
- The work required to maintain an appropriate environment and support team around people with behaviours of concern can be significantly higher than for others. This work translates into higher costs. These include the additional time required to recruit, roster, train and support staff and work with families and the input required from case managers, clinicians and managers to underpin these processes. Flexibility is also necessary to respond to unanticipated and sudden changes in the level of support required and to deal with what are often volatile situations. If this additional work is not effectively managed the appropriateness of support and people’s satisfaction with the support they are receiving can deteriorate and behaviours escalate. This in turn generates further work in terms of increased rates of incident reporting and their management, complaints and their investigation, property and vehicle damage and risk to the morale of the workforce and the provider organisation’s reputation.
- The research raises concerns that unless true costs are reflected in price setting the development of a disability support market will introduce market incentives to ‘cherry pick’ those people with lower level support needs. The market may also fail to guarantee services and/or a safety net for those with behaviours of concern while threatening the economic viability of provider organisations that are supporting large numbers. This could result in higher charges, poorer outcomes and a lower quality of life for those with behaviours of concern whilst eradicating their choice and control.
- The National Disability Insurance Agency (NDIA) wishes to construct pricing mechanisms which are based on what is known about good practice in working effectively with participants and where individual funding packages reflect the real costs of support. This research challenges the current pricing assumptions for supporting people with behaviours of concern. The NDIA/NDS work to introduce a unit or ‘efficient’ price based on transparency about price assumptions has addressed some of the additional costs generated by those with behaviours of concern. However this research demonstrates that significant necessary and foreseeable unaccounted costs remain and would not necessarily be met under the current efficient price modelling. This suggests that providers risk being inadequately funded to deliver the supports participants require. This will put a severe strain on provider organisations working with people with behaviours of concern and hence on the ability of the market to provide choice and control to these participants.

# RECOMMENDATIONS

This report acknowledges the current work being undertaken by the NDIA to ensure that additional costs incurred by supporting participants with behaviours of concern are taken into account in pricing mechanisms. The following recommendations support and affirm these developments.

**Recommendation 1:** That mechanisms for an ongoing dialogue between service providers and NDIA planners and administration be fostered and promoted.

**Recommendation 2:** That NDS/NDIA undertake a detailed time and motion study to fully assess what is involved in providing support to participants with behaviours of concern.

**Recommendation 3:** That the reasonable cost model incorporate a 'higher intensity plus' rate for participants with behaviours of concern.

**Recommendation 4:** That a template be developed for providers and planners to raise awareness about the criteria for attracting higher intensity plus rate and complex care coordination in order to better assess individual funding packages.

**Recommendation 5:** That providers have access to a contingency or 'brokerage' fund which can be used to contain situations in the shorter term.

**Recommendation 6:** That block funding be available to enable investment in capacity and innovative approaches, for example in accommodation options, prior to the completion of the NDIA planning process.

**Recommendation 7:** That providers working with participants with behaviours of concern be able to consider the option of salaried support workers to provide higher quality support.

**Recommendation 8:** That care coordination should be provided by the primary support provider when supporting participants with behaviours of concern.

# 1 INTRODUCTION

The introduction of the National Disability Insurance Scheme (NDIS) marks a significant social and structural change and a transition from a welfare system to a social insurance scheme. It has been described as the biggest social and economic reform since implementation of the original Medicare scheme and has generated significant public support.

Since the inception of the scheme it has been anticipated that those who are able to effectively negotiate their support packages will benefit significantly from the NDIS. It will increase the choices available to them; they will be able to 'shop around' to find a service provider that best meets their needs and aspirations; and they will have control over their own lives to an extent that would not have been possible previously. At the same time concerns have consistently been raised by a range of commentators and particularly by service providers about how those participants<sup>1</sup> with behaviours of concern will fare and whether the NDIS will be able to provide them with choice and control over how their support needs are met (Productivity Commission 2011; NDS 2013a).

Using the experiences of two provider organisations – Anglicare Tasmania and Optia – this research examines in detail what is involved in providing support for people with behaviours of concern and how this experience can be considered within the NDIS.

The research was carried out by the Social Action and Research Centre (SARC) during 2014 with advice and support from a Research Reference Group. The Group included representatives from the National Disability Insurance Agency, National Disability Services, the Department of Health and Human Services in Tasmania, Optia and Anglicare.

## 1.1 What are behaviours of concern?

This report is concerned with the small number of people who have behaviours of concern. For the purposes of this research this group are defined as:

People whose behaviour generates a series of indirect or transaction costs beyond direct support costs which are not included in the current standard price list for the NDIS. This may include people with co-morbidity, cognitive/communication limitations, acquired brain injury, intellectual disability or autism. They may put themselves or others at risk, demonstrate verbal or physical aggression, damage property and vehicles, have self injurious behaviour or have families with complex issues. For the purposes of this report these indirect costs are described as 'unaccounted costs'.

This is a very diverse group and includes individuals with all levels of learning disability and cognitive issues, different sensory or physical impairments, mental health issues, communication and personal relationship issues. They may have been involved with the criminal justice system and/or engage in behaviours that are harmful to themselves or others.

The term 'behaviours of concern' is intended to emphasise that problems are often caused as much by environmental factors and the way in which a person is supported as by their own characteristics (DH 2007). Behaviours therefore are not a problem to be fixed but a sign that something is wrong and not working for the individual, that a need is unfulfilled or that there is a communication problem (NDS 2014). 'Severe behaviours of concern' refers to behaviour of such intensity, frequency or duration that the physical safety of the person or others is likely to be in jeopardy or limit or delay access to and use of ordinary community facilities (DH 2007). People with behaviours of concern can require intensive support over a long period of time. It may be months or years before some are successfully supported to achieve fully inclusive outcomes and the behaviour of a minority can present a serious concern for much of the time throughout their lives.

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<sup>1</sup> Throughout this report the term 'participant' is used to refer to people with disabilities who are in receipt of services.

The number of people with behaviours of concern is small in any given location. Some people have such behaviours all the time but many more move in and out of this group depending on changes in their circumstances and how well services are meeting their needs. Estimates vary but it is likely that there will be 24-40% of adults with an intellectual disability per 100,000 of the total population who will exhibit episodes of behaviours of concern in any one year (DH 2007; Fyffe 1999). A smaller group will exhibit severe behaviours of concern frequently and present an exceptional challenge to services. Based on these estimates it is likely that about 24 adults per 100,000 total population present a serious challenge to services. This means that in Tasmania approximately 120 people will present with a history of severe behaviours of concern in any one year (McClellan 2012). Unless services are able to effectively respond they can take up a disproportionate amount of time and money for provider organisations. It is this group that are the focus for this research.

The complexity of the NDIS profile being seen by provider organisations may be changing and increasing with more complex health needs, dual disabilities, alcohol and drug issues and people who have contact with the criminal justice system (NDS 2013b). This may increase the small numbers of people with severe behaviours of concern. Their numbers may also increase if inappropriate support is provided to those with less complex behavioural issues.

## 1.2 Choice and control in the NDIS

Prior to the introduction of the NDIS Government agencies contracted service providers directly through annual block funding or case-based funding arrangements to deliver disability support services to participants who met certain criteria or who were referred to the provider as part of an individualised plan and/or individualised funding package (ISP). In Tasmania individuals entered the system through Gateway (a service out-sourced from government to the NGO sector three years ago) which undertook an assessment of needs and then negotiated with services to get these needs met and re-negotiated as and when needs changed. There was often little participant input into decisions about the level of support required, how that support was managed and who delivered it. The person using services became a passive recipient of rationed supports from providers (Productivity Commission 2011). Any additional or uncounted costs generated by people who presented with behaviours of concern could be managed through cross-subsidy between individuals. This allowed providers, including Anglicare and Optia, to maintain a high tolerance threshold for behaviours of concern.

The NDIS puts people with a disability and their families at the centre and individuals not service providers receive their own individualised funding package to spend as they see fit on 'reasonable and necessary support'. A participant and their family and/or carers will have 'control and choice' over decisions and develop a plan with an NDIA (National Disability Insurance Agency) planner based on their individual support needs, goals and aspirations. The plan specifies agreed supports and the funding required to deliver them. It is intended that the system is uncapped and that the services received reflect true need rather than the availability of resources with all costs correctly and completely absorbed by the relevant individual packages of support (Saward & Dawson 2013). The quality of the assessment and planning process is key in ensuring appropriate and effective support.

The NDIS is being introduced gradually across Australia and full roll out of the full scheme nationally will commence progressively from July 2016. In Tasmania from July 2013 the scheme has been available to approximately 950 young people (aged 15-24 years) with a significant and permanent disability and who meet residence requirements.

However as a disability support market is progressively introduced it raises questions about how participants with behaviours of concern and who generate a range of indirect or uncounted costs for providers will fare. On the positive side putting people with behaviours of concern in charge of their allocated funds will potentially

impact on behaviours, confidence and capacity and in the longer term on support costs. At the same time any failure to properly reflect fixed and uncounted costs in price setting will be problematic for both providers and participants. There are concerns that a disability support market will:

- Introduce market incentives to ‘cherry pick’ those participants who require low level supports, are easy to manage and where staff require no particular qualifications;
- Fail to guarantee services for particularly vulnerable participants leading to under-servicing and unmet need or to local monopolies which may overcharge;
- Be unable to guarantee a safety net if the support system around those with behaviours of concern collapses;
- Threaten the economic feasibility and stability of provider organisations who become providers of last resort supporting large numbers of participants with behaviours of concern whose costs are not fully covered; and
- Fail to provide a broad range of services from which to choose for those with specialised support needs.

For participants with behaviours of concern a disability support market could mean high uncounted costs which are then reflected in the form of higher charges, poorer outcomes and a lower quality of life whilst eradicating any choice and control.

### 1.3 Anglicare and Optia

Anglicare is the largest community service organisation in Tasmania operating a range of programs across different sectors. These include crisis services, accommodation support, employment services, mental health services, acquired injury, disability and aged care services. About one third of its business is in the disability support sector. Through Anglicare AT HOME it provides support for over 400 people with disabilities to live as independently as possible and achieve their goals. Services include:

- supported accommodation in eight shared homes for groups of two to six people;
- personal care and support to access the community for people living in the community;
- services to assist people to develop daily living and life skills;
- specialist intensive support services working with people with behaviours of concern and complex needs; and
- comprehensive case management/care coordination services.

As well as accessing support from the DAAT team<sup>2</sup>, in-house expertise about how to manage behaviours of concern is provided by Anglicare’s Practice Support Unit (PSU). Staff act as consultants to case managers and will assess and develop behaviour intervention plans for those with behaviours of concern, train staff to support their practice and assess environments in shared homes.

Optia is Tasmania’s biggest disability services provider specialising in working with people with intellectual disability. It offers a wide range of services across the state including a large residential sector and supports over 350 people with disabilities through:

- supported accommodation providing a long-term shared home environment for groups of two to five people;
- respite accommodation providing short-term support and accommodation for people with disabilities;
- community support giving clients personal assistance and development opportunities with daily living skills through to broader life skills including social and relationship skills;
- semi-independent living for clients who want to live independently but who frequently need informal support to do so. Support might be needed with emotional, social and decision making issues;
- leisure and recreation programs to encourage and support people to develop friendships and social networks in the wider community;
- specialist support services to assist those with behaviours of concern and complex needs that exceed the scope of other disability programs. Specialist staff are trained in positive behaviour support.
- out-of-home-care for children with additional needs which mean they cannot be cared for by foster families.

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<sup>2</sup> The Disability Assessment and Advisory Team is located in the Department of Health and Human Services (DHHS). The team supports registered clients of Disability Support Services through assessments and consultancy advice on disability related issues to provider organisations.

Optia has a Practice Development team that provides in-house expertise about positive behaviour support. This may entail consultation with staff teams to undertake functional assessments and develop positive behaviour support plans, liaison with professional support services and relevant agencies to conduct external assessments, overseeing the implementation and review of positive behaviour support plans and the training and development of staff.

## 1.4 Aims of the research

The test of the NDIS model is whether it can not only work for people whose support needs are straightforward and stable but also for people with complex, unstable, unpredictable needs and where their capacity to indicate their preferences may be limited. This research aimed to investigate how far individualised funding and the disability support market is able to offer choice and control to people with behaviours of concern. In particular it aimed to:

- Define and quantify the real and often hidden or uncounted costs of supporting people described as having behaviours of concern;
- Assess how far these costs are currently covered on transfer to the NDIS;
- Investigate the implications of transition to the NDIS for participant outcomes and provider organisations where there are behaviours of concern;
- Review how a range of community service organisations are identifying and dealing with these issues; and
- Make recommendations about how to ensure that participants with behaviours of concern can be effectively and adequately supported through the NDIS.

## 1.5 Research methods

The research used qualitative methods to explore in microcosm what is involved in meeting the support needs of participants with behaviours of concern. It entailed:

- **Identification of current and recent participants described as having behaviours of concern** in Anglicare and Optia services. This proceeded through a state-wide meeting in each organisation with case managers and practice consultants where current case lists were compared with the definition of behaviours of concern (see page 5). This ensured consistency over how the definition was applied across case-loads. Those identified included current and recently exited clients as well as those in receipt of individual support packages (ISPs)<sup>3</sup> and NDIA funding packages.
- **An exploration of the uncounted costs** of supporting people with behaviours of concern. This proceeded through a series of regional focus groups with case managers/practice consultants. The focus groups explored the challenges of supporting these participants, the way in which uncounted costs cluster around particular participant characteristics and provider hopes and concerns for these participants on transfer to the NDIS. A number of key stakeholders were also interviewed about the issues involved in working with behaviours of concern. Stakeholders included managers in provider organisations and key informants in agencies involved in managing the transition to the NDIS.
- **Compilation of case studies.** A number of the participants identified have unique histories and characteristics which are well known to services in Tasmania. In order to preserve their anonymity whilst also providing a basis for exploring costings nine fictional case studies were compiled. The case studies highlight the range of issues, behaviours of concern and support needs of these participants and are designed to be as representative as possible of Anglicare and Optia participants who have behaviours of concern.
- **A review** of how these issues are being addressed in a range of community service organisations (CSOs) in other jurisdictions and specifically targeting Anglicare Australia member organisations involved in providing disability support services. CSOs in WA, ACT, Victoria, SA and NSW were invited to participate in a telephone interview with the researcher. This included organisations located in NDIS launch sites across Australia.

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<sup>3</sup> Individual Support Packages are managed by the Individual Funding Unit in the DHHS. They are funds allocated to a person to meet their disability-related support needs. The individual can choose the support they need, the service that provides that support and how and when the support is provided.

- **Costings.** The case studies were used to estimate the uncounted costs of providing support to participants with behaviours of concern. This work drew on the expertise of the finance departments of Anglicare and Optia (see Appendix 1 for the costing methodology).
- **An analysis** of the ability of the disability support market to support participants with behaviours of concern and ensure they have access to choice and control in meeting their support needs. This included exploring a range of possible solutions to mitigate any potential risk of market failure.

## 1.6 Limitations of the research

There are a number of limitations to this research.

- **The perspectives of participants, their families and carers.** The research findings are based on the perspectives of service providers. It was anticipated that participants and their families would be unlikely to recognise the uncounted costs borne by provider organisations in supporting those with behaviours of concern. They may well however have strong views about the impact of behaviours of concern on their ability to exercise choice and control in a disability support market place. This is a valuable area to explore in any future research.
- **The use of ‘fictional case studies’.** This was driven by a need to preserve the anonymity of people, many of whom would be highly recognisable in a small state. This represented a challenge in undertaking the costings which were necessarily based both on a series of assumptions and the monitoring of a range of actual costs over a period of time. The costings produced provide a reliable guide to the nature and extent of the additional uncounted costs faced by provider organisations supporting those behaviours of concern. They also form the basis for devising sustainable mechanisms for monitoring these costs in the longer term.
- **Uncounted costs.** It is understood that the uncounted costs generated by supporting people with behaviours of concern are a mix of participants’ individual characteristics and the extent to which they are being effectively and appropriately supported. Effective support and interventions can have a positive impact on behaviours by preventing problems arising in the first place, managing them effectively when they do and reducing the challenge they represent to services and hence the costs. This report assumes good practice on the part of Anglicare and Optia in supporting these participants and hence that the organisations are not investing disproportionate amounts of time and money through ineffective or inappropriate practice and/or environments.
- **Operational differences between the two organisations.** This could potentially affect costings and these differences were explored. They include different approaches to case management, awards applied, rostering and professional input in terms of managing behaviours of concern. It is emphasised that all the providers interviewed for this research reported challenges in supporting participants with these behaviours. In this sense the costs identified will be encountered by any provider organisation working with behaviours of concern and will not radically differ according to operational models.

Finally this is a rapidly changing environment. This research was based on participants using services in April 2014. Yet not only are new participants rapidly transitioning into the scheme but, as the Productivity Commission has acknowledged, establishing the NDIS is an ‘unfinished project’ and there are lessons to be learnt from launch sites during each step of the process. It is intended that these learnings will be integrated in a continuous and ongoing manner into the national roll out of the full scheme. This has already led to a number of changes in NDIA operations including how prices for items of support are set. These changes begin to address some of the concerns voiced by providers supporting those with behaviours of concern.

# 2 PEOPLE WITH BEHAVIOURS OF CONCERN: NINE CASE STUDIES

## 2.1 Behaviours of concern

People described as having behaviours of concern are very diverse and present in variable ways depending on their life experiences, different stressors, the quality of their lives and co-morbid health or mental health issues. The causes of behaviours of concern can include a history of neglect, abuse, living in a restrictive environment or be an outcome of the disability itself combined with low expectations on the part of support staff or family (NDIA 2014). There are those with complex and challenging needs that may need less direct personal support but require high levels of service coordination (Fitzpatrick 2010). There are others who have periods of low level behaviours of concern which can often be addressed through good assessment and the development and implementation of behavioural strategies.

One of the greatest difficulties in working with people with behaviour of concern can be their sensitivity to small changes in their environment or health. Their need for security, predictability and consistency can escalate behaviours and make their situation volatile. When things are not going well this can mean intensive support and interventions for a temporary period followed by a period of stabilisation and reduced support. For many, episodes of behaviours of concern will reoccur throughout their lives and escalate when their environment changes. Supporting them appropriately means minimising the need for them to communicate through behaviours in the first place and managing behaviours when they do occur to ensure the safety of the person and those around them. It also means implementing strategies for increasing the skills of support staff, providing supportive environments and reducing and preventing behaviours of concern in the longer term. Overall behaviours of concern will be better or worse depending on how good the person's quality of life is and how well those supporting them understand their needs.

## 2.2 Developing case studies

Anglicare and Optia support a number of participants who are identified as having behaviours of concern (see "Research methods" on page 6).

From discussions with case managers/practice consultants about supporting these participants nine case studies were developed. The case studies demonstrate the range of characteristics, behaviours, environments and support issues which Anglicare and Optia are managing. They include people living in a range of different environments – in the community with their families, living in shared housing or in their own homes with varying levels of support. The case studies include people with mild or borderline intellectual disability and mental health issues and those who have had contact with the criminal justice system. Some have had a history of abuse and present with the same needs as anyone else in order to cope with these histories and experiences in addition to their needs relating to their specific disability.

**Table 1** Number of participants with behaviours of concern

<b>Region</b>	<b>Anglicare</b>	<b>Optia</b>	<b>Total</b>
South	9	8	17
North	8	6	14
North West	0	22	22
Totals	17	36	53

Note: up to six of these participants were new to services and their support needs had not as yet been fully assessed.

The case studies were divided into three different levels depending on the level of support and intervention required in order to provide a good quality service – very high intensity, high intensity and stabilised but with the potential for behaviours to escalate. Depending on external factors like life changes or changes to their environments participants with behaviours of concern can cycle through these three levels at different times.

## 2.2.1 Very high intensity

### Tracey

Tracey is in her mid-forties. She lives in her own unit in a high support cluster of units and requires 24-hour support. She has autism and an intellectual disability. There are mental health issues and some OCD type behaviours. There are also health issues associated with being overweight and diabetic. She is a large woman and when she gets upset she can be angry and aggressive towards staff, other residents and neighbours.

She attends day support five days a week. When she gets home at 3pm a staff member is with her until 8pm when she gets ready for bed. Staff sleep over in her unit and provide support until 9am the following morning when she leaves for day support. At the weekends she receives support up until 11am and then again from 3pm until she retires. She will only accept female support staff and currently there are 10 staff on her support team.

There are significant hygiene issues and she can refuse to shower or to use the toilet. Her fear of losing things means that she prefers to toilet in containers which she then deposits in her unit. A lot of prompting is then required to clean up after herself although she can do it. These issues mean the continual washing of clothes and the costs associated with that in terms of water, power and washing powder where she only finds some brands acceptable. Food is also an issue and she finds it difficult to control her appetite. This combined with the unsanitary conditions in her unit have meant that food is prepared for her elsewhere and she chooses and collects it daily. One recent addition has been the purchase of a large wheelie bin. This helps with her tendency to hoard rubbish and she is prompted to fill the bin on a regular basis.

If her routine is followed she can be 'a dream' to work with. But there are a number of triggers which can unsettle her and escalate her behaviours. These include disruptions in her support team, having too many people around or having new people on site. When unsettled she can become violent and aggressive towards staff, property, neighbours and other members of the community. This has resulted in considerable damage to her unit, including smearing with faeces and broken furniture, cutlery and crockery. In the past month over 20 incidents have been

reported including punching people, running naked in the local streets, damaging staff and neighbours' vehicles and property and throwing things at taxis. She has also issued death threats to neighbours which combined with damage to their property has put her at significant risk of threats from people in the community. There are times when she barricades her doors and refuses to allow staff to enter. It can take several hours to persuade her to open the door. This means that the simplest of tasks can take a long time to complete and staff have had to resort to climbing in and out of windows with all the accompanying WHS issues that entails. When she is unattended at the weekends she makes repetitive calls to staff and leaves screaming messages and threats to kill people on the answer machine. She has been known to dial 000 repeatedly.

Because of damage to vehicles, staff are now unwilling to transport her in their own cars and day support are unwilling to transport her home due to a number of violent incidents towards their staff. This has meant a doubling in the cost of taxis and not all taxi companies are willing to take her because of her reputation. It also means that staff are unable to park on site. This creates difficulties for staff returning to their vehicles late at night.

These behaviours mean regular contact with the police, the complete refurbishment of her unit and considerable costs in terms of cleaning products and equipment like protective clothing for staff, gloves and boots which are required continuously. They have also meant a high turnover in her support team and difficulties in filling her roster. Only the most resilient staff have survived generating additional costs in terms of staff recruitment, training and 'buddying in' new staff.

In order to regulate her behaviour and move beyond 'firefighting' there has been considerable input from clinicians to develop specific protocols and behavioural strategies. Staff are then trained in their implementation through input from clinicians at staff meetings and in ongoing refresher sessions. Clinicians are also involved in monitoring the implementation of strategies to ensure that protocols are consistently applied.

These interventions are having a significant positive impact on her behaviour although consistency in their implementation can be difficult to combine with a high turnover of staff in her support team.

The case management task has been considerable and as her case manager said on some days 'one thinks and lives and breathes Tracey'. There is a large network of people around her who require coordination as well providing support and debriefing to staff working in a very challenging environment. A key factor for the case manager has been maintaining a good working relationship with her family who are very involved in her care. Some of the concerns expressed by the family have led to formal complaints requiring management time, including the involvement of senior managers, to oversee investigations and responses and liaise with the Department although in some cases the issues have been minor or unsubstantiated.

## Mary

Mary is a teenager with an intellectual disability and a brain injury which she acquired as a child. This means she finds it difficult to anticipate the consequences of her actions. There is also a psychiatric history resulting from abuse from the age of four from her mother's boyfriend. She has had contact with the justice department and the police as well as a history of homelessness and association with people involved in criminal activities. Recently there have been weekly suspensions from school due to hitting or threatening staff or other students. In a heightened state she will threaten self-harm. There are also some medical issues due to her diet and lack of exercise.

She is currently living in her own unit in a cluster of 17 for people who can manage semi-independently with varying levels of support. This includes support from 3pm to 9am weekdays and also at weekends with a sleepover shift. At times the sleepover becomes active and although staff are not paid for waking shifts there are regular sleep disturbances. Outside her support hours she will often make contact by telephone when she is bored, depressed or emotional. This can mean hours on the telephone discussing self-injurious behaviours often associated with her family. These conversations have been a very important valve for her to debrief and to keep her stable.

People like her and are attracted to her but she can be difficult to work with. She currently has a support team of 18 people. She rapidly identifies who she wants to work with but can also quickly change her mind and a careful match is required between her and her support team. She can become abusive to staff and refuse to have them support her again.

Further demands have been placed on her support roster due to her suspensions from school which mean additional day time support is required. She has also stolen from staff and there have been instances where she has injured them. In one case this led to a workers compensation claim. There have been 10 reported incidents in the past month. This has meant a high turnover in her support team and difficulties in recruiting new staff due to her reputation.

Her behaviours have meant considerable investment in staff training in order to understand her behaviours, know how to handle situations and recognise when things are escalating and how to defuse it. Due to her difficulties in recognising the consequences of her actions rewards programs have had little impact and clinicians have been involved in devising behavioural strategies. This has increased the number of staff meetings in order to provide training around specific behavioural protocols and ensure consistency in their implementation.

The case management task has been particularly taxing – up to 60 hours a month – and it has taken considerable time to build a collaborative relationship with her and her family. Her lack of patience means that she often fails to turn up for appointments and this has involved staff in escorting her to appointments and in booking new appointments. As her case manager said *'pretty much every day is a risk management day for Mary to keep her safe. At the moment she is my life. I can have a week that is Mary, everything I do is Mary.'*

## Brett

Brett is in his early twenties. He is autistic, has ADHD related behaviours and an intellectual disability with a mental age of about five years. He also has delayed speech and is mostly non verbal but impulsive and has difficulty focusing or paying attention. He is diabetic, incontinent and very food orientated. He will eat anything including plastic containers, the soles of his shoes and his shoelaces or anything which is left on the floor. He has also eaten staff belongings.

Brett has 24-hour support in a high support house with a sleepover. He attends day support five days a week from 9am to 3pm but there have been days when staff at day support have returned him because they are unable to manage his behaviour. This has implications for the staffing roster in his

accommodation and means additional support has to be provided. His case manager describes him as *'a bomb, you just don't know when it's going to explode and when it does explode he has the capacity to really harm you. You can never go into the house and think it's going to be a smooth sail tonight, you always expect the unexpected.'*

Brett is a large man and when he is heightened there have been a number of incidents of violence towards staff and other residents including pushing, hitting, the tearing of clothing and bedding and chasing staff around the house. A particularly dangerous time can be during showering when he can strike out at workers and/or get them in a headlock. He recently wrestled one support worker onto the couch with his arm at her throat. Because his behaviour can suddenly escalate staff are often asked to remain beyond their shift to provide additional support to resolve challenging situations safely. He likes to go for walks but managing his behaviour in the community and protecting the public can be difficult and requires two staff. He does leave staff supervision and can be quick and strong but has no road or water safety knowledge or understanding.

As well as aggression towards staff there has been substantial property damage. He has damaged two units, a number of buses and other vehicles. This has been a big drain on police and ambulance services. In one incident he kicked holes in the plaster and pulled quantities of it off the walls to use as a weapon against staff. This required fitting reinforced plaster throughout the house in the lounge, hallway, kitchen and bedrooms. Household items like furniture, crockery, cutlery, pots, pans and glassware have had to be regularly replaced alongside bedding and clothing. These incidents have led to two workers compensation claims and the involvement of senior managers in defusing situations.

There has also been a complaint from his family about an unexplained bruise. The investigation of the complaint entailed meetings between staff, the family and the area manager. It also involved the services of an external investigator when the family were unhappy about the outcome of the internal investigation. The complaint was eventually found to have no substance.

Brett can be exhausting to work with and not everyone is able to do it. This has meant a high level of burnout among support staff and a limited pool

of staff who are prepared to join his support team. Although the team has been fairly stable it is a very difficult environment for new staff. There has been DAAT and in-house clinical support to manage his behaviours and to develop a comprehensive plan and behavioural protocols. The turnover in the team accentuates the need for continual and ongoing training and monitoring of behavioural interventions. The case management task is substantial and requires considerable liaison with the police, support to staff and out-of-hours work.

Transport has been a key issue with Brett. A history of hitting, scratching and biting staff driving the car and other passengers has meant he has to be transported separately. At times he has also soiled himself in the vehicle and then smeared. This means that as well as the costs of additional trips and increased fuel consumption professional cleaning is also required.

## 2.2.2 High intensity

### Jamie

Jamie is in his early twenties. He is autistic with a mild intellectual disability and through much of his life has been classified as disruptive, difficult to work with and not deserving of services. He has a very complex family situation. His mother has an intellectual disability and schizophrenia and found parenting difficult. This meant that Jamie had many disruptions in his life and has spent much of his childhood moving in and out of foster care placements and living with grandparents. He is fairly high functioning in terms of living skills which has meant that his autism was often overlooked. He has issues with anger and aggression and there may be some undiagnosed mental health issues. He is on probation and there are concerns about his capacity to understand the terms of the probation or remember appointments with his probation officer.

Jamie is currently living with his grandmother who is in her seventies. He attends day support and thrives when he has a solid routine. However issues with his family tend to trigger escalating behaviours. These include ripping and shredding clothing and bedding, damaging furniture and other domestic items and damage to windows. He has also been involved in lighting fires. Over the past few months a number of incidents have been reported.

There are times when he refuses to care for himself or to shower and refuses to engage with day support. When he does get angry he displays a hatred of anything with authority. This has resulted in several incidents where he has attacked police cars and broken windscreens. At these times the case management task is significant and there are intense spikes when he absorbs all of his worker's time for a number of days. The work has entailed a lot of liaison with other services and with advocacy and one of the most time consuming aspects is working with his family. This has required a lot of negotiation with the family about their capacity to support him in maintaining his routines and about what is best for him in the longer term.

Difficulties with his family have put strains on his support team and at one point required a restraining order to be taken out against an uncle who was making sexual approaches to support staff. This has meant significant pressures on the case manager to support and debrief support workers.

There has been involvement from in-house clinicians to develop behavioural interventions. This has also required developing protocols to moderate the behaviour of his mother so that it does not trigger escalations and then working with her to implement the protocols. His grandmother has been very supportive in this work.

Jamie's support team have also found autism awareness training of great benefit in improving their capacity to meet his needs. He hopes to transition into his own unit in the near future. This accentuates the importance of maintaining a consistent support team who are trained in his particular needs.

There are concerns however that, despite building a stable and trained support team, there is a risk that he may be returned to prison or put on remand in the coming months.

## Anthony

Anthony is 20. He has a mild intellectual disability and some other physical health conditions including diabetes. He is quite high functioning and is independent in terms of his personal hygiene and domestic tasks like cooking and cleaning although he does require prompting. He displays socially inappropriate sexualised behaviour which is related

to trauma experienced during childhood but is very sociable and loves meeting new people. However his behaviour also means that he requires a number of restrictions to protect himself and others when he is in the community including not going into public toilets by himself.

He is currently living in a high needs house and requires one-on-one 24-hour supervision. He attends day support five days a week.

Changes to his environment trigger behaviours and he can then become a risk to himself and to others. Many of these escalations can be prevented by providing scheduled activities and social events but a number of protocols have also been developed to deal with his sexualised behaviour and lack of boundaries so that staff know exactly what steps they should be following and how to respond.

His case manager spends a significant amount of time ensuring that staff are following protocols and that he is operating in a socially acceptable way. The case management role also entails a lot of collaboration with other professionals including day support and the DAAT team to ensure a consistent approach.

Because he is pleasant to work with the turnover in his support team has been low and staff morale has never been an issue. But there is a constant negotiation required about what he can or cannot do unsupervised.

## Sarah

Sarah is in her thirties. She has a mild intellectual disability and some physical health issues including arthritis. She experiences high levels of stress and anxiety and there are concerns about undiagnosed mental health issues. She has the necessary life skills to be able to live semi-independently.

Sarah lives with her mother and has an individual support package (or ISP) for 21 hours of support per week. She also attends day support. She would like her own accommodation. One of the key issues for her support team are her regular heightened emotional states when she expresses suicidal tendencies and can threaten self-harm. These behaviours can escalate and result in a stream of calls and contact with the office, with support workers, coordinators and case managers. It is not unusual to receive up to 40 calls

over a weekend threatening suicide. There can also be a number of calls to the police and to ambulance services and she may drop into the office two or three times a day. The calls are often loud and abusive and can entail making false allegations against staff which then have to be investigated. These behaviours have made it difficult for her to form relationships with others and this leaves her isolated from the human contact which she seeks. Although her package does not include any funding for case management, dealing with this level of contact with staff and liaising with police, ambulance services and the local community means a significant input of time and energy which can double her allocated support hours. It also has a big impact on staff morale and stress levels and has increased the turnover in her support team.

The DAAT and in-house clinicians have been involved in devising strategies to intervene in these behaviours. There have also been a number of court orders to restrain her and limit her contact with people around her.

Sarah's behaviour has led to a number of complaints from neighbours and the community and from her own family. Her mother has rung staff in distress and time has been spent in providing reassurance. At other times the family is difficult to get hold of and many hours can be spent in trying to make contact and in rearranging missed appointments and unanswered phone calls. Episodes have resulted in formal complaints from the family and multiple calls to support staff and managers. Two months ago the complaint escalated into direct contact with the Minister. Senior managers then became involved in overseeing an investigation, progressing discussions and responses and supporting and debriefing staff so that they could continue to maintain a working relationship with the family. This meant a considerable expenditure in time from across the organisation.

### 2.2.3 Stabilised/cyclical

#### Sean

Sean is in his twenties. He has an intellectual disability, is autistic and also non verbal. He has a Guardian to manage his affairs. He has also had contact with forensic services due to an assault charge

involving a worker from his previous day support provider. Risks around him reoffending remain and he is easily led and suggestible.

He is currently living in the Intensive Support Unit with 24 hour supervision. He used to abscond on a regular basis and much time was spent in liaising with the police, locating him and returning him to his accommodation. Over the past year a combination of a stable staff team, few changes to his environment and the thorough implementation of behavioural protocols have stabilised his situation. However just recently his absconding behaviour has returned triggered by the arrival of some new staff and a new resident moving into the facility. Two staff are required to supervise him effectively when he is in the community.

It is anticipated that he will be able to improve further over time with the appropriate support and as long as the capacity to provide that support is maintained. There is a large network of people involved in keeping the situation stable including his Guardian, advocates, the forensic team and hours of emails and meetings. The risk is that as his situation further stabilises he may appear to need less support than he in fact does and for his support levels to be reduced triggering behaviours of concern.

#### Jackie

Jackie is in her early thirties. She has an intellectual disability and eats excessively. This means she is obese which has led to other health issues. She has also been referred to a psychiatrist for assessment of possible bipolar disorder and she finds it difficult to express when she is angry or depressed. When she becomes unsettled there are some self-harming issues.

Jackie lives in a shared home with 24 hour support. She attends day support and has two staff in the mornings and evenings. For some years now there have been a core group of staff who work well together and are familiar with all the signs which can trigger her behaviours. They all receive a higher level of pay because of the training and skill levels required including training around the specific needs of supporting someone who eats excessively. However when new staff arrive it can unsettle her and trigger behaviours. This can mean she will scream, slam doors, close her blinds and generally shut herself off from staff and other residents. It has resulted in some damage to property and furnishings. This

creates problems in introducing new staff into her team. Those who are inexperienced in working in challenging environments often only last for two or three shifts.

Part of stabilising Jackie's situation has been extensive support from clinicians to get behavioural strategies in place. This now means that after two years of intervention she can manage without an active sleepover shift. These strategies and protocols require ongoing refresher input to ensure they are being followed and interpreted in the correct way. This process is monitored by the case manager.

However while the situation is currently working and she is managing well, it is also volatile. This makes it a necessity to stay on top of the situation because it is fragile and once things escalate it can require considerable resources to restabilise it. When she is distressed she can make numerous phone calls to rostering staff and to the case manager. As one worker said 'it is the eggshells that are managed behind the scenes' which keep the situation stable.

## Mathew

Mathew is in his forties. He is autistic and non verbal and was previously resident at Willow Court. He has an intellectual disability, a very short attention span and anger issues which he finds difficult to control. He can be hard to engage. His affairs are managed by the Public Trustee.

Mathew has 24 hour support in a shared home and attends day support three days a week. He needs assistance with most of the daily tasks but is very familiar with and committed to his routines. This means he likes to assist with tasks like making a cup of tea, preparing food, doing his washing or getting ready to go to day support. Some of his behaviours impact on neighbours. These include peering through their windows, touching their mail or going through their rubbish bins. There are now a number of strategies in place to assist with his behaviours including communication programs which are continuously developed.

Mathew has admissions to hospital two to three times a year for several days. When he is in hospital there is no funding for his support in the shared home despite the fact that his support team are involved in maintaining contact with him and providing the

things he needs including clean laundry. In addition he requires extensive support when any dental work is undertaken including an anaesthetic and a trip to the hospital with support staff in attendance.

There have been transport issues. He is tall and unless he is transported in a roomy vehicle where there is plenty of leg space he can feel crowded and behaviours can escalate. His tendency to dribble and spit in the car and in the house mean that there are ongoing costs for cleaning products and professional cleaners.

Recently staff have had to implement some restrictive practices to control his obsession with food. This obsession means that he will hunt cupboards, the fridge and rubbish bins for food which he then eats. As well as locking the kitchen in the short term staff have been intervening by setting up a compost heap on site. This means that any tea bags or other suitable food he finds can be torn up and added to the heap. This has given him more control over food and his compulsions.

There have been a lot of positive changes for him in the past year and his situation is now more or less stable. But this has required a multi-disciplinary team and high level skills from the case manager. Some of his support team have burnt out in the process.

# 3 WORKING WITH BEHAVIOURS OF CONCERN

The NDIS means that the individual funding packages that participants receive are intended to be a true reflection of the real costs of supporting participants guided by NDIA pricing levels. The cost per hour of supporting a participant with behaviours of concern will vary enormously in terms of their characteristics and volatility, the number and skill levels of staff required, their training requirements and recruitment costs, input from in-house clinicians and a range of consumables like equipment. This raises a risk of a gap between the NDIA price list and the actual cost of providing support which is borne by provider organisations. This risk is potentially higher for participants with behaviours of concern. If these gaps are not funded provider organisations will eventually have to decide at what point providing support to an individual becomes unsustainable.

This chapter takes a close look at providers' experience of supporting participants with behaviours of concern, what uncounted costs this might generate and how these costs might impact on other parts of the organisation. It includes examples from participants currently supported through block funding arrangements as well as younger participants who are transitioning into the NDIS through the Tasmanian launch site.

## 3.1 Establishing and maintaining a support team

Support workers are recruited through the flow of resumes coming into organisations, through general recruitment drives and through advertisements recruiting for specific individuals and which ask for demonstrated experience of working with people with behaviours of concern. Participants are involved in choosing the staff they wish to support them and may express preferences in terms of age, gender and personality. An effective, stable and consistent support team is vital in supporting people with behaviours of concern and once a team is in place maintaining it, covering sick leave and annual leave, skilling up and supporting staff can be more onerous and time consuming than for other kinds of participants.

*We do a number of meet and greets but the clients may not like them or click with them so we need to put more people on. If the client likes them that's great and then the support worker also has to be happy with it once they've done a few shifts as well.*

The key to an effective support team is matching the support staff to the participant and paying close attention to skill level, training and experience. If the match is right there are few problems, the support team is stable and works well together and time spent on rostering decreases.

*There are a core group who work with her. They have been doing that intensive support for a considerable number of years and the ones that have stayed are obviously fairly resilient. We have noted over time that consistent behaviour and consistent support workers have managed to keep the behaviour, not at a minimum, but less of a problem. Consistency does work. Clients attach to people and they want the same person. Staff that come and go have never worked before with someone with challenging behaviour so they don't tend to hang around too long. It's not a massive turnover but it doesn't take long for a person to realise they don't want to be there, only a couple of shifts really.*

However inevitably staff move on or the roster needs to incorporate sick leave and annual leave and replacement or temporary support staff. Participants can find dealing with change difficult and a new member of their team or having too many people around can create anxiety. If in addition the match is not a good one it can result in escalating behaviours and incident reporting. This means that rostering for these participants can be particularly time consuming.

*If you don't get the mix right you're in big trouble. With Jake we had to have certain staff with him. Not everyone can work with him, it's very hard. You can't just pull anybody in because it will just heighten the situation or make it more explosive and then we've got more behaviours and*

*the repercussions of that. He is autistic and he had a flamboyant support worker, very talkative, very active, not a literal person. Jake doesn't understand that, you need to be literal and there was an over stimulus with movement and the way she talked. It didn't work. You have to be very specific about who works with who. If people are put in who are not suited to those clients then we get repercussions, behaviours and incident reports. It takes a certain skill set to work with these clients.*

*Rostering is about setting up your days, times, staffing and everything that goes with that. For those who present with challenges more people are involved and more time is spent in terms of filling the shift which comes out of other stuff people should be doing. The time spent building the right roster is exorbitant. One day we spent six hours just on one client to fill a shift. How do you put a figure on that? Records will tell you who is rostered when but not how long it has taken to find someone to fill a shift. When staff become unwilling to support a particular client or drop their shifts at the last minute or the client refuses to be supported by a worker any longer, hours can be spent trying to fill those shifts with phone calls and emails but this is not budgeted for.*

These difficulties with filling rosters can be accentuated by the volatility of participants where their behaviour and hence their support needs can change at short notice and require an immediate and flexible response:

*Sometimes he wakes at 3am, sometimes at 4am, sometimes at 2am. So the staff have regular sleep disturbances which are not covered by his funding. The staff are up from that time but are not paid for waking shifts. So that is a cost the organisation has to carry. We have to pay staff because they are woken during the night.*

*He has physically attacked staff in his day support. We get a call from day support wanting to return him because they can't manage him. But we don't have the funding between the hours of 9 and 3 as he's funded to be somewhere else. If day support want to give him back we have to foot the cost of it which is not in his plan.*

A key characteristic of working with behaviours of concern is high turnover in support teams. This is promoted by the volatility of participants and a less than optimal matching of support worker and participant which exacerbates burn out among support workers. A high turnover then reduces the size of the team and increases pressures on existing support staff which furthers the incidence of sick leave and burn out.

*People get burnt out a lot more quickly with these clients because it takes a lot more out of you. They are very challenging, difficult people to support. It's emotionally draining. Sometimes she's a dream, sometimes she's threatening to kill your family, swearing at you for hours. Even the most resilient person gets worn down by that. She might like a staff member today but not tomorrow and will say I won't work with this person. And then when that person goes there she will do \$3,000 worth of damage to their car and you can't send them there again. With other clients you might have the same staff going there for 10 years.*

*With her we have had a number of staff go through burn out. Just working with her on a day-to-day basis for a length of time is incredibly difficult. You see lots of compassion fatigue and then you have situations where staff are hurt or the person makes really significant threats to them and they just feel we don't get enough money to do this. What they are really saying is that they don't feel safe anymore. When that happens with staff over time you have fewer and fewer staff that will support that client or know how to support that client. One way of dealing with this is to try and even the load and put more people on but there is a cost in that. We ask a lot from our support staff and sometimes I think we have expectations of them which are unrealistic.*

Trying to reduce high turnover rates means ensuring that staff have access to a break and to support and debriefing if they require it. This can mean spreading the load by expanding the size of the support team in order to facilitate a slower rotation of shifts. For example one of our case studies had 10 core staff but over a

period of a month probably up to 20 different people were involved in her care. Providing opportunities for staff to debrief was seen as an essential part of sustaining a support team but the time required was not necessarily set aside or formally recognised as a core part of the work.

*Debriefing is very important but never gets recognised. Working with the more intense people, apart from staff meetings there is no real allocation for any sort of debriefing time. Staff are expected to come on shift at 3 and finish at 11. There is no time allowed outside of that to say they did well or talk about the situation they faced that maybe was scary. Staff meetings happen once a month unless there's a need which again is an extra cost and sometimes four weeks after an incident is far too late. All our managers would make themselves available if someone needed to debrief, but staff won't because there is no provision to be paid for it. So instead they don't do it and take it home so the cost of not having that debriefing falls on their family, their friends, their lives.*

The impact of this can mean that rostering staff or other office staff may, by default, be filling the gap:

*Staff call you crying over what they've just experienced. We are not supposed to debrief staff but if they ring up, what are you supposed to do, you've got to give them something. And as much as they need to debrief, while I'm on the phone listening to them I am not working at getting somebody there. They don't know what to do and they ring us. We get stressed because they are out there in danger. If we tell them to leave so they don't get hurt we can't leave the site unmanned so who do we get? It all becomes a big pressure situation.*

All these factors can have a big impact on the morale of both direct support staff and rostering staff. As one case manager said:

*They are good staff but they get so they feel used and abused and they just want to duck out. They don't want a career doing this. You rely on them to hang back after their shifts and do things but the mental effects that some of our clients have on staff is pretty high. It requires a certain resilience to work in this area.*

In order to encourage retention staff working with these participants require a recognition of the higher skill levels and training required with higher levels of reimbursement.

A key outcome of high staff turnover is the impact on recruitment processes and introducing new staff. Although it may be more difficult to get a good match, the process of recruiting a support team for someone with behaviours of concern is not necessarily higher than for other clients. It is the fact that recruitment is required more frequently due to higher turnover, having to organise additional meet and greets and to integrate new workers into the team. This escalates costs. Once staff are recruited buddy and orientation shifts are organised to introduce them to the participants and their support needs and it is always an unknown whether a particular support worker will 'bond' with a participant. Some new staff will do one or two shifts, encounter a difficulty and leave. The recruitment and orientation process then has to start from the beginning.

*When you have a high turnover it means you are continually having to buddy in staff. That cost is not covered because clients are only funded for direct support from their staff. The fact that you are having to introduce new staff because a lot of them get burnt out means that you are always looking for new staff to go in and we seem to be relying more and more on staff that may not have all the experience we would like them to have. People working long term know all the triggers and signs. With new people who are getting to know the ins and outs it can cause behaviour because a new person can make them so unsettled.*

With increasing numbers of young people coming into the NDIS through the launch site demand for younger support workers is high but difficult to meet. This in turn can mean higher turnover rates for younger workers in support teams as the demands and pressures on them increase.

## 3.2 Care coordination

Most participants identified with behaviours of concern do require care coordination. The care coordinator can be vital in order to ensure that support teams are functioning as effectively as possible and that they get the support and leadership they need. This role also involves:

- Coordination of support networks – sending emails, making phone calls, organising meetings, collating and disseminating information to other service providers;
- Liaison with other services – for example, police and ambulance services, day support, clinical services;
- Inputting into the NDIA planning process and transitioning of clients;
- Training, supporting and debriefing support staff, overseeing the implementation of behavioural protocols;
- Dealing with volatile and crisis situations as they arise; and
- Working with families and other carers.

They may be overseeing a participant's transition from school or their family home into the community, finding suitable accommodation, working with advocates, addressing restrictive practices, identifying the specific support needs of new participants or making a support plan a reality. It can be difficult to anticipate the time that should be allocated to care coordination particularly where situations are volatile and as one case manager said 'how long is a piece of string'. Situations can stabilise and the care coordination task decrease but there is always the possibility of behaviours escalating given the right triggers – staff leaving, new staff arriving, a death in the family, changes at day support, a new neighbour, a new house sharer.

*There is a lot of coordination work, staff training, debriefings, meeting all her medical and psychiatric needs and liaising between everyone and making sure things get done. We are allocated 10 hours but I can have a week which is just Mary. Some days one thinks, lives and breathes Mary. Other times things will go along quite smoothly. She calls every afternoon about what she had for lunch and to run through things. For people like her there is not really ever a lull. But for others there are intense spikes where life becomes that person for several days and you just have to deal with the crisis, get a plan, make sure it's implemented and then you can move on.*

The volatility of participants presents an ongoing risk and care coordinators need to marry the demands of working constructively with those who can be very challenging on a daily basis with the needs of staff for emotional and practical support.

*There are clients we support who at times in their lives needs a full time case manager. There will be periods where they are very escalated and destabilised. They will calm down and then something will happen and you need to go back to that almost full time support. When you are trying to maintain a group of support staff around that person and to respond to all the issues that presents it's a lot of work. Unless you look after your direct care workers then you lose them.*

*There is a risk that if he's travelling okay and doing well it can seem like he doesn't need as much support as what he's getting. There is the potential to drop the support level. We have had nearly a whole year without him absconding. Then all of a sudden it's reappeared and become an issue again. There are lots of different factors involved. He recently met a new friend who he's been obsessed with, he's got a new house mate. Changing his environment can increase his behaviours.*

Like support staff, the pressures of the care coordination role brought about by behaviours of concern can escalate until they have an impact on morale, heighten the risk of burn out and impose further pressures on senior managers to provide support.

*Being on call 24/7 for these clients means you start to get exhausted. As case managers we get phone calls at the weekends that we don't claim for. We don't get time off, there are always out of hours calls from clients, from the workforce. Last weekend I got one phone call and four emails. The one before I worked for four hours on the phone. We do the work but we don't get reimbursed and this is every weekend.*

The necessity for the active management of participants with behaviours of concern means that difficulties can arise when the care coordination function is provided by an organisation other than the primary support provider. This creates challenges in performing some of the core functions of care coordination – resolving crisis situations through the direct supervision and oversight of support teams, pro-active and preventative work and the role modelling of good practice. Active day-to-day risk management also requires regular oversight and review of incident reporting and maintaining good working relationships with families. Given these functions a strong case can be made for care-coordination to be performed by the primary support provider for participants with behaviours of concern.

### 3.3 Working with families

Many people with behaviours of concern will have families who are involved to varying levels in their support and families can be a crucial factor in a participant's support network. Although work with families is currently not captured in the NDIA price list an effective working relationship with a participant's family can be vital to achieving good quality support and good outcomes for participants. Developing and then maintaining these relationships can be demanding and time consuming depending on the complexities and needs of the particular family which are typically high. Case managers/care coordinators described being involved in:

- Counselling families, for example when their child leaves home for the first time;
- Facilitating positive relationships between family and support staff;
- Managing conflicts of interest between the family, the participant and support staff, especially when their aims and goals differ;
- Involving the family in decision-making;
- Negotiating the sharing of case management roles with the family, for example who attends appointments with the participant; and
- Building the capacity of families to promote positive behaviours and implement protocols.

This work can entail managing constant communications, phone calls and on site contact. The family can have very different views and opinions about how things should be done and what the participant wants and what their family wants can be very different. Negotiating how to work together with the family in the best interests of the participant can take up an inordinate amount of time. As two case managers said:

*When we've got everything settled and it's solid we virtually don't have any issues with him. But he can escalate and the family thinks I know him so I can de-escalate by calling and texting. It can actually make it worse. You set up a routine, the family break it and this causes behavioural issues. So when you have a client you're not just managing them, you are actually liaising with and being an advocate for the whole family. It's holistic care. You have to build good trusting relationships with the family and that takes time.*

*If you have a family member who is that person's responsible person you absolutely have to maintain a strong working relationship. Sometimes that's incredibly difficult and it takes a lot of time and effort. I'm not sure that's a cost NDIA will be prepared to fund.*

When issues with families remain unaddressed misunderstandings between support staff and families can escalate into formal complaints. These then require investigation which can incur significant additional costs, especially when the involvement of senior management is required.

The NDIS places a strong emphasis on facilitating community access and inclusion. However currently this does not necessarily take into account promoting positive access to and contact with family.

### 3.4 Managing behaviours and training

Behaviours of concern develop for many reasons and can be the result of a history of discontinuity in relationships and bad experiences in relating to others.

*Some of the people we support not only have an intellectual disability but a really significant trauma history and/or a mental health diagnosis. That mixing together then makes their presentations challenging for us and particularly when we have disability support staff trained in knowing how to support people with disabilities but not trained in supporting people with trauma histories and mental health conditions. Sometimes people are so highly wound up and agitated and distressed and scared all the time because of their history they are always on the verge of having a meltdown and then they become aggressive, threatening. When someone presents like that regularly it's so challenging for our staff to work with them. If people go in untrained the behaviour can get violent, they don't know how to contain it, they don't know what to do. To work with someone like Diana you need to have knowledge behind you about her and how to handle situations, think on your feet, recognise that the situation is escalating and how to redirect and avoid it. Staff like that are rare.*

Disability support workers are not necessarily trained or equipped to deal with people who exhibit behaviours of concern. Training however is an essential ingredient in providing effective support for these participants and this can often mean a heavy investment in training direct care staff to respond to behaviours of concern in ways that minimise its likelihood and severity. Preventing the development of or worsening of behaviours is a priority because of the impact on the participant and those supporting them if the severity continues to increase or become ingrained. So as well as ensuring staff are supported through supervision and debriefing they also require technical support from clinicians in how to work with behaviours of concern and to effect change through the way in which they respond to situations and behaviours.

The experience of providers has shown that investing heavily in stabilising people with behaviours of concern can substantially reduce costs in the longer term if the right support is put in place (Crates & Spicer 2012). This can be a long term goal and may take years to achieve before the situation of some participants is stabilised – up to five years or more. Yet without this investment the only other option available may be a restrictive environment like prison or a psychiatric facility at a very high cost. There are other participants who may exhibit lower level behaviours and where change and a reduction of costs can be effected by the development and implementation of consistent strategies over shorter periods of time; for example eradicating the need for active sleepovers or restrictive practices.

*Much time and effort can go into managing someone's behaviours so they can actually move forward and lead a rich and meaningful life. With one client we put in a year's worth of work and that person is now doing incredibly well. Unless you are prepared to go in for the long haul and see it through half-hearted behaviour interventions are not going to cut it for many people. When people do behaviour interventions with two or three months involvement things will fall down a year later and you have to do the same thing again and again.*

Providers like Anglicare and Optia need to ensure a high level of competency in working with behaviours of concern. Both organisations have invested in senior staff with expertise in current best practice who undertake ongoing professional development including conducting peer reviewed research. These senior staff oversee comprehensive functional assessment and the development of behavioural support plans, provide assistance to staff in implementing, maintaining and tracking the progress of these plans and provide training in positive behaviour support and participant-specific training. Other training provided to staff working with these issues may include PART training (Predict, Assess and Respond to Challenging/Aggressive Behaviours) or SAFE training (focusing on appropriate behaviour within the community) as well as additional training focusing on autism awareness, complex health problems, first aid, social role valorisation and positive behaviour support which may be accessed through external organisations. In order to offer a good quality service to participants with behaviours of concern provider organisations need to be able to offer this kind of supervision, coaching and training to their staff.

Participant-specific behavioural support protocols require consistent and sustained implementation by staff over many weeks working as a team and keeping a careful record of events and incidents. This means that once staff have been trained in the protocols assistance is required to implement and maintain them through clinical oversight, a leadership role from the care coordinator and on-going refresher courses. This work needs to run alongside effective orientation for new staff so that they are able to experience these behaviours and ways of dealing with them whilst being supported by other workers. Clinicians also need to respect the knowledge gained by staff in working daily with individuals and the effectiveness of strategies.

A key mechanism for training staff and implementing and monitoring behavioural interventions is the staff meeting. Establishing a new behaviour management strategy, managing the behaviour of a particular participant or managing a situation where behaviours have escalated may require increasing the frequency or in some cases doubling the number of staff meetings, to discuss and revise support plans and protocols with a significant input of time from clinicians. This can mean meetings dominated by the needs of one participant while the needs of other participants are not necessarily addressed.

*For complicated clients ten hours of staff training is never going to cut it in terms of the support needs of the services which support them. You might be able to write a report but that's the easy part. It's the implementation of strategies over time where everything falls over consistently, that is the hard part. You can never transfer that report onto the ground unless you are prepared to put the time into it as a clinician. So much work has to go into working with a group of people. They have to trust you, you have to listen to them, you have to really put time into developing that working relationship to make it happen. You also have to be available to staff to come back and say you know how you said to do that, it didn't work. Then you need to see what else you can try. When someone is 40 and has been engaging in entrenched behaviours all their life there is going to be nothing easy in working out what will impact on their behaviour. There will be some clients who will need a clinician working in the background, if not the foreground, for a good year. If you think a psychologist is \$160 an hour, that's incredibly expensive.*

*If you have to double the number of staff meetings to contain a situation we absorb that cost. You say to staff I know it's your day off but we have to have a meeting. There's an impact on the quality of the workplace and people's workplace conditions and they seem to deteriorate the more complex a client is. Our staff meeting turns into a four hour meeting and then you need one the next week and the week after because you need more information. The cost involved of five to eight staff for two hours isn't funded under NDIA plans. For these clients they are vital so everyone is on the same page. A staff training package may be eight hours but that may not be enough to train one person with the skills let alone a group of four plus the other fourteen you need. And then there's the ongoing nature of training where you are always updating.*

Even when staff are well trained to follow behavioural protocols results can be short lived because it is difficult for them to maintain compliance with protocols and consistency over long periods of time especially if there is no clinical oversight. This raises the risk of occupational health and safety issues arising. In situations where there already is high staff turnover ensuring consistency in the implementation of behavioural strategies becomes a continual problem. It is also a problem when provider organisations take on new participants in crisis. There may only be a few hours to put support in place and no time to prepare and train staff. This can mean putting staff into situations where they have to 'free style'. This can increase burn out and turnover rates and the risk of escalating behaviours.

*We have to make sure that the right processes and protocols are in place but staff won't stay long enough to see the protocols working. It's difficult to send in new staff because they won't follow protocol and we need to reinforce the protocols. So there may be a lot of people putting out fires and then leaving. But what happens is we give the new staff the more challenging clients with the least amount of individualised training for that particular client because we have to fill the shift.*

Effectively managing behaviours of concern then requires a significant investment in supporting staff and in training. It not only includes the actual cost of developing and delivering training including participant-specific strategies and clinical input but also the cost of an increasing number of staff meetings, removing staff from front line roles, covering their shifts and paying them to attend training courses. For a number of people with

behaviours of concern this investment needs to be long term and as one case manager said 'there are few quick wins'. If this work is not specifically commissioned from a provider organisation it becomes an indirect cost which is borne by the provider.

### 3.5 Managing the impact of behaviours of concern on staff, other participants, property and vehicles

When people with behaviours of concern become distressed or things are going wrong for them it can trigger behaviour that is aggressive, threatening or violent towards both people and property. When these situations arise staff, other participants and members of the community such as neighbours can become the target of physical and verbal aggression. There may be a minor physical injury from being shoved, scratched or having hair pulled. Furniture and other objects may be thrown or the episode may have been entirely verbal in the form of threats. There can be a higher rate of injury with new staff as their inexperience means situations are more likely to get out of control.

*I hurt my back because he pushed me into a door frame and if the flying plaster had hit we would have had an OH&S issue. There are a couple of vulnerable people in the house that he could knock over at any time in his rampage, he doesn't think. You can never go into the house and think it's going to be a smooth sail tonight, you always expect the unexpected. There may be ways to mitigate it or alleviate it but not a way to remove it completely. The only way would be if we didn't have him and that's not something we're prepared to do. Some of these clients have gone through every provider and have come to us.*

*A client might be expected to use public transport but if they are running up to people and threatening to kill them or choke them you can't safely always take them on the bus. One minute you're walking down the street and the next minute he's grabbed someone.*

Targets can also be property with damage to accommodation and contents where furniture and crockery is broken and blankets and clothing shredded. In some cases it has required the complete refurbishment of units. One participant eats anything which is left on the floor including plastic containers, the soles of his shoes and the laces and staff belongings. Staff have had their belongings taken or broken. Neighbours' properties can also be damaged. This then makes the participant and the organisation a target for a neighbour's frustration and distress.

*Any time a worker is not standing in the room with her she would be over at the neighbour's house. She got his mobile number which meant a lot of calls. She damaged his fence, his car. She would leave rubbish in his front yard. She broke his barbeque. We are not legally responsible for her so it's a police issue if she does damage. But that leads to the neighbour being quite aggressive towards her and puts her at risk. There are threats to her and she makes threats to other people.*

*He has trashed five units, three buses and two cars. The DAAT team put reinforced plaster in the lounge room, bedroom and hallway. He pulled all the plaster off one wall and kicked holes in the plaster. He did about \$8,000 worth of damage in the house. He has to pay off that \$8,000. He gets his DSP and \$10 per fortnight and everything else goes on paying off his debts.*

Damage to vehicles includes scratched bodywork, windscreen wipers and wing mirrors torn off and broken and soiling in the car.

*He attacks cars and there are times when he's soiled himself in the car and smeared in the vehicle. Then we have to have it professionally cleaned. There is also the impact on other clients. So instead of making one trip we have to make two because it's not safe to transport other clients with him. He needs one-on-one which is staff time and adds to the cost of fuel and the upkeep of the vehicle.*

*Staff get their vehicles damaged and they can't get to work or they are not allowed to drive because they don't have rear view mirrors. They may have to park up the road and then we have staff at night walking to and from their vehicles knowing the neighbour is really unhappy with Anglicare and with him. There is so much potential for things to go pear shaped.*

*She is expensive to transport because staff don't want to take her in their cars because she damages them. Not all taxi companies will take her because of her reputation. Taxis come, see her and keep on driving. Day support no longer drop her home because there were too many violent episodes towards staff. So she is paying for twice as many taxis and it's expensive.*

Theoretically if a participant breaks something deliberately they would be expected to pay for it. Yet participants are dependent on the Disability Support Pension and not only is this likely to take many years, making further deductions from what are already small incomes can run the risk of further escalating behaviours. All staff are required to have comprehensive car insurance. Minor damage and repairs where the costs fall below the organisation's insurance policy excess are covered by the organisation. More costly damage to staff or neighbours' cars requires lodgement with their car insurance for malicious damage with the organisation reimbursing them for the excess. However if there is a likelihood of this most staff are unwilling to use their vehicles because insurance claims lead to increased premiums which result in further cost. This may also lead staff to place themselves at risk to protect their property leading to a higher risk of injury. In these situations the only option for providing transport may be for the organisation to supply a vehicle.

The majority of incident reports relating to behaviour of concern are about the psychological rather than the physical effects and the support worker and/or other participants are shaken and require support. Incidents of this nature would result in OH&S staff working with case managers and house coordinators to undertake an investigation about why the incident occurred, what triggered it and what strategies or protocols can be put in place to prevent it happening again. This means that the organisational costs of incidents of verbal and physical aggression to people and to property manifest in the staff time involved in incident reporting and investigation, staff stress and sick leave, workers compensation claims, higher staff turnover rates in support teams and difficulties in recruiting new staff where a participant has gathered a reputation. Incidents also generate costs in repairing damage to property and vehicles and potentially additional transport costs to facilitate community participation. Added to this are the costs of additional staff time to support a participant at the police station or at court.

There are also those participants who may be receiving low levels of direct support but the level of contact they demand from the organisation can spiral into large indirect costs. There are times when an organisation may make a decision to absorb some costs to minimise time delays in dealing with incidents and prevent increases in insurance premiums.

*She lives independently because she has the skills and she gets 14 hours a week but in reality she is probably receiving 38 hours on a regular basis. She drops into the office three or four times a day and it can be nothing to receive 30 or 40 calls from her over the weekend. She can make up to 500 calls a week. There may be threats of self harm and then you have to act on it. If we took that away from her so she didn't have access she would become a higher risk. We've tried everything to control it and she has court orders against her for ringing people. What she is seeking is not extreme, she wants human contact but no matter what we organise for her to get that contact she destroys those relationships. She costs us a fortune in time but that is not captured anywhere.*

Lastly behaviours of concern can generate a range of additional costs through the heavy use of utilities, modifications required to manage particular behaviours, dietary requirements or only being prepared to use certain brands of washing powder, soy milk or cereals.

*She has a thing about washing her clothes and they get worn out very quickly. She will run a washing cycle with only one thing in it because it's caked in poo. So much water and power and washing powder is used.*

*We have had to do modifications to her unit like putting up a fenced barrier so she can see out but we can't see her. We also put a roller blind on her front window because she was sure people could see her naked when she was in the bathroom. In the grand scheme of things it didn't cost much but the maintenance man had to come and fit it but she wouldn't let him in. So a task which should have taken 20 minutes took hours.*

As other commentators have identified (DH 2007) a goal of eliminating behaviours of concern is not necessarily achievable. Yet an increased focus on the management of risks to the health and safety of staff and other participants can potentially mean people being denied opportunities to live their lives as they would like in order to avoid risks to individuals and to organisations. Managing this tension between the risks of behaviour and the risks of a reduced quality of life is a delicate balancing act.

### 3.6 'No shows' and lack of engagement

A substantial indirect cost for provider organisations is funding those instances where it has not been possible to deliver scheduled support to a participant. For participants with behaviours of concern this can be due to a resistance to engage. They may refuse to open the door, be absent or abscond. Although contracts with participants specify the notice required to cancel a shift they may cancel outside these time frames.

*She has been known to barricade the doors and not let staff in. That is difficult when they need to get her to take her medication. Staff may be prompting her to let them in for over an hour.*

*You are booked to pick up a client from TAFE and when you turn up they are not there. They've absconded because they've had an upsetting day. You have the extra travelling but also you may have lost your shift without being informed. It's not your fault. We still have to pay our staff but we're not getting anything for it. Under the award we need to give staff a minimum of two hours notice or we still need to pay them. And we can't claim it back or invoice for it because we didn't provide a service.*

There are also instances where participants have been hospitalised. This leaves a support team who although unable to provide direct support are still involving in maintaining a relationship with the participant.

*You train staff and then the person goes into hospital. We can't bill for support they're not receiving but someone still has to do the laundry while they're in hospital. Workers thought they had 30 hours a week but are dropping back to 20. There is still a need for support to continue relationships with staff, to maintain consistency and for staff to be reinforcing behavioural interventions. The nurses can't provide that support and they have no experience of working with these types of disability. So we end up supporting them and there's a real cost to that. How do you build a support team around that?*

Until recently the NDIA specified that no fee was payable for a support that is not delivered regardless of the reason or the period of notice given. It was anticipated that this issue would be addressed by assisting participants to be responsible, imposing fees and penalties in an educative process and by more flexible employment arrangements for staff. This generated concerns among providers that these situations were often beyond their control and that it would mean that no one would want to work with those participants who presented a high risk of no shows or refusal to engage. The NDIA have recently reviewed the cancellation policy to allow providers to claim for unreasonable cancellations or 'no shows'. They are still exploring the issues created by 'no shows' and lack of engagement on the part of participants.

### 3.7 Managing risk to the organisation

Supporting participants with behaviours of concern can generate a series of risks to the operation and reputation of provider organisations. Effectively managing these risks incurs indirect costs.

At an operational level the most serious risks are to the safety and wellbeing of both staff and participants and what that means in terms of maintaining reputation and accreditation. Many of these risks and ways of managing them have already been discussed – appropriate training and skill levels for support staff, behavioural interventions, ensuring appropriate environments and policies and procedures for managing incidents. Ultimately managing these risks can potentially lead to discussions about how viable it is to offer support to those with behaviours of concern given the balance required between the organisation's resources and indirect costs and the goal of providing high quality services. This group have the highest risk of placements breaking down. While turning people away may reflect badly on an organisation's reputation the damage to reputation from a serious adverse incident, for example a car accident caused by behaviours of concern and leading to a death, is far worse. It is only possible to support those with behaviours of concern or those who might be seen as high risk clients if there are appropriate skills within the organisation and adequate funding to develop appropriate mitigation and prevention plans and implement these consistently.

*We want to deliver the newest care in the best way for good client outcomes. But we may actually have to refuse someone because we're not organisationally ready for that client. Is it better to walk away from these clients and tarnish your reputation because you said no or to say yes and do it badly. If we are going to say yes we have to have the infrastructure in place to be able to deliver the job. If we can't deliver down the track then we look bad.*

Operational difficulties can lead to complaints; from staff and trade unions, other services, participants and their families and from the broader community. In serious cases this can result in ministerial involvement and negative reporting on the front page of the newspaper. Because behaviours of concern can impact on a range of people outside the primary support team and because these participants tend to have a large network of people involved in their support this can increase the frequency of complaints and generate a broader profile of complainants. As one manager said:

*You get to the point where you accept that the nature of this work means that a lot of complaints come with it. The management and administration of complaints can form a significant part of what I do. These clients and/or their families are more likely to complain because there are many dynamics around the reasons they are being supported. There is guilt from the parents about not being able to cope and never feeling other support will be good enough.*

Complainants want to know that senior personnel are involved and taking it seriously. This means that managing complaints can require a large time commitment from senior management. There is an investigation at area management level and senior managers are kept informed of how it is progressing. Complaints and the investigations required can generate additional staff meetings, emails and multiple phone calls. There may be discussions with the Department of Health and Human Services and/or threats to take legal action or involve the media. If a participant receiving four hours of support a day and their family complains, managing that complaint, conducting an investigation and providing a response can be the equivalent of appointing a full time manager for that participant for several weeks. A significant invisible expense is the opportunity cost or the time spent not doing other things and in a fixed price commercial environment an organisation cannot afford to neglect other participants because they may then seek alternative providers. There is also the stress and emotional impact on staff which can be severe and as one case manager said 'the family were telling her she wasn't any good at her job which is a really stressful thing, that feeling that what you're doing is not good enough'.

*A family member is unhappy about something that has occurred and a complaint comes in. They might have sent an email with a lot of other people copied in. It goes up through the management structure and the story is repeated numerous times and there is an investigation. It might be that staff have to be contacted about the incident. It might involve travelling to the other side of the state for a face-to-face. You need senior people in the room to support the managers. People can go to the Minister's office or they've reported it to the Department. We then have to work out how*

*to respond. It's extremely time consuming and the CEO might be copied in. One client smashed a neighbour's car over the weekend because she thought it was one of the support workers. They were on the phone demanding the CEO's number.*

Effectively managing complaints means developing a proactive process which minimises the risk of a complaint being made and prevents situations from escalating. This process entails reinforcing positive relationships and communication mechanisms, keeping information on file and better managing participant and family expectations to promote more respect between parties. Overall it can mean a significant investment of time in developing good working relationships with families.

*It's about ensuring there are appropriate relationships at the right level and that the family and the case manager have regular communication so there are no surprises. It means setting up a weekly meeting to take the heat out of it and managing the relationship in a very deliberate and proactive way so if there is an issue you can ring up and deal with it straight away instead of it festering. There is always going to be a time investment in managing relationships with these clients. It's how you manage it so it doesn't become this big issue that then takes up so much time and so much expense.*

Once the reputation of the organisation has been damaged and it enters the public domain it can be difficult to counter. This can affect a participant's or their family's choice about who to purchase support from as well as the ability of the organisation to recruit new staff.

*A lot of support workers work in different organisations and they talk about the tough clients or the management of those clients. Word gets around and staff can go in fearful and the client picks up on that within seconds and you're out and we have to introduce more people. Other workers may say don't work there and so they don't want to meet the complex clients.*

One way of managing risk to reputation is to invest in strengthening the organisation's profile.

*Building a strong reputation is a way of reducing or eliminating that risk and that costs money. So our branding and marketing generally helps in building our reputation. We have just spent \$xx,xxx on television advertising which will build that brand and help give us that resilience in the market place.*

In summary for organisations working with people with behaviours of concern building and maintaining a positive reputation can be problematic and require financial investment.

### **3.8 Transitioning to the NDIS – choice and control for people with behaviours of concern**

Since July 2013 Tasmania has been the launch site for the 15-24 year old age range. This means that both Anglicare and Optia now have a body of experience about the NDIA planning and review process and how this might be promoting the choice and control people with disabilities have over how their support needs are met.

It has always been anticipated that there will be 'teething problems' with participants, planners and providers feeling their way as increasing numbers of people transition into the scheme. As well as positive experiences of the NDIS, where people with disabilities including those with behaviours of concern are given a range of options and high quality support, providers also identified a number of indirect costs for them in participating in the scheme. These costs can be incurred as existing clients transition into the NDIS, when potential clients approach them for support or during NDIA review processes. These costs are more likely to be incurred by participants who have behaviours of concern as their support needs are more complex and difficult to assess.

Firstly support staff and case managers may be involved in supporting existing clients to participate in the NDIA planning process. This can entail helping them to fill out forms, meeting with the planner and other stakeholders and inputting information.

Secondly, accessing high quality support depends on having accurate information about a participant's needs and wants, a quality plan and adequate funding. Given that a plan defines people's lives providers were finding that there was often a deficit of detailed information. Case managers commented on shortcomings of the planning process where plans failed to take into account essential information about mental health issues, complex health and behavioural issues or capacities. The information only became available after the organisation had established a support team and in some cases only when it was proactively sought by a case manager. Providers had found themselves taking on participants who had significantly less in their funding packages than they actually required. These risks can be particularly high when working with people with a mild intellectual disability who are articulate about their goals and claim a range of skills and capacities which they do not have. This can mean that they end up with a support package which is almost independent living because actual capacity is not taken into account. In some cases organisations had refused to provide support because the funding package was not adequate. There were then concerns about the quality of support they were receiving when the participant negotiated support from another organisation. This also generated concerns about the time taken to negotiate support with a participant who then decided to seek support elsewhere. These issues translate into additional case management hours and hence additional cost which are not covered by the NDIA. There was also managing a potential risk to staff in meeting new participants with little background information.

*Initially the information can be scarce or is missing. There are people who require one-on-one awake shifts but that's not being captured in plans. When NDIA interview the client they capture them on one day. That day their focus might have been on going to the movies. In fact they may only really want to go to the movies once a year but the plan ends up with a big focus on going to the movies. It means that when a person comes in you almost have to go back and redo the plan because they are under-supported in different ways. If you talk to a client they may give you a very different version of what their skills are in terms of being able to live independently. The case manager may be going out on their own to meet someone who you know has been incarcerated but you don't know the reasons why.*

*Some individuals interview a number of case managers. That's fine and at the moment we can wear it but if that's two hours of my time to potentially not get a client how do we cover that? This is one of the unfortunate things about being in a competitive environment, that we have to sell ourselves and increasingly that means we have to send people out without any financial compensation.*

Thirdly, staff emphasised that they learnt more about a new participant in the first four to six weeks of supporting them than during any intake process. This means that the NDIA review process and its flexibility, where the size and nature of the funding package can be altered, becomes critical. Some staff reported good experiences of NDIA reviews resulting in the offer of increased support hours which had been backdated. In other cases there was a lot of uncertainty about whether funding packages would be increased in line with provider perspectives about the support an individual required and which they had been delivering and if so whether it would be backdated.

*Someone comes in with a low support package and very few hours because they are deemed to function really well. But in actual fact they require quite a bit more support. As an organisation we end up wearing those costs. We ask for the plan to be reviewed, put the support they need around them and hope that it gets approved. We might put in 10 hours per week of case management over six weeks but there are no guarantees that that will come through and if it does will it be backdated?*

These uncertainties were exacerbated by numerous questions about what costs the NDIA would recognise and cover and the interface between the NDIS and other systems. In relation to participants with behaviours of concern this included:

- the real costs of designing and implementing positive behaviour interventions;
- staff time in managing relationships with families;
- managing high staff turnover in support teams and the need for ongoing training;
- managing high levels of risk to staff or property; and
- whether behaviours and their impact in terms of cost are seen as part of a disability or not.

*One guy has fallen off the roof and hit his head because he lacks capacity to judge risks. When you talk to NDIA and say he's broken his hip they say that's not an NDIS problem, that's a health problem. Well the health problem is due to his capacities. There is no flexibility with the plan.*

*If there is a client with a moderate intellectual disability, a diagnosis of OCD and they are charged with an offence, how would NDIA view the support issues that come out of the mental health and forensic mental health side? Will they say that's part of their disability? There's not a lot of point in pulling it apart too much because it all goes back to that person's trauma history, how they respond to the world, what makes them feel unsafe and what makes them so challenging for us. That is further compounded by the intellectual disability. People run into problems with the police because of a lack of understanding about what's okay and because terrible things happened to them as a child. How will NDIA work out what to fund? If forensic mental health say they need anger management will NDIA fund that as part of their disability?*

Clearly these concerns are all part of the early stages of implementing new systems and processes. Yet they are also generating a series of uncounted costs which are currently being absorbed by provider organisations, at least in the short term. If these costs continue to be unfunded or underfunded from individualised support packages the risk is that participants with behaviours of concern will become too expensive to support and providers will make decisions to turn participants away or withdraw support. This limits any choice or control for participants and also has a big impact on the reputation of organisations who are not seen as being flexible or accommodating.

*My fear is for those people who don't have support and can't work the system. As organisations we will have to be more business-like and turn away people who under previous models we would have provided for. It it's not doable under the funding that NDIA provide then who is going to do it? Is it going to be someone who might be less client-orientated or cowboy organisations that provide support that is not of the same quality?*

Lastly providers raised concerns about the capacity of participants and their families to make informed choices about the quality of care or about their ability to change providers – a key aspect of being an informed consumer in a market place. This was seen as demonstrating the cultural shift required to transition from a rationed system of supports to one based on entitlement.

*It's recognised in plans that if you want to change you can but I just don't think people do. It's not easy to pack up out of a group home and go over to someone else, but it's doable. But once you enter an organisation there are not many who would leave. The theory is nice, and has always been there but in Tasmania where else are they going to go? With Terry for instance there are other day support options but due to her volatility I don't think anyone else would take her. There are difficulties associated with changing provider when you've got a disability and a minimal support network, how easy is it going to be to actually make that change happen? Are they just going to give up and say I'll just stay here because it's easier rather than struggle to find a new service? What is their capacity to change providers?*

### 3.9 Experiences of community service organisations in other jurisdictions

As part of the research we explored the perspectives of Anglicare Australia member organisations in other jurisdictions about supporting people with behaviours of concern and the uncounted costs they generate. We spoke to services in jurisdictions which had been NDIS launch sites since 2013. We also spoke to services in jurisdictions which were only just entering the NDIS and described themselves ‘at the tip of the iceberg.’ All said that they were currently supporting a small number of participants with behaviours of concern and raised anxieties about how these participants would fare under the NDIS.

*We are in the middle of a unit costing exercise and we will be much more zoned in to what it actually does take us to provide support now we can no longer rob Peter to pay Paul. We have one person who self-harms. They are on an individual support plan but if we actually calculated everything we do over and above that most of it would be around the amount of coordination time and intense case management time. At times I think we are unconscious to these costs because we have made it all work with block funding arrangements. We are waiting to see how things unfold.*

*At present we are very involved in the planning process from the beginning so we know what we are getting into and can build in indirect support like case management. With people with challenging behaviours we would try to put a big team around them so you aren't putting pressure on one or two people. When we work in this very individual way and the person is given choice and control a lot of the behaviours don't escalate. A lot of work goes into finding the right person, making sure the relationship works. Our fear is that when the planning is done externally these things won't be taken into consideration. Someone will say here is Fred and he's funded for 40 hours direct support which we then find is not sustainable.*

In jurisdictions where services had more experience of the NDIS concerns were expressed about the level of uncounted costs they were encountering.

*We have a fairly clear view that many of our clients don't receive enough funding to provide adequate quality services to them. For those that have become known as one-to-one, the NDIA business model just doesn't work and that's where we have our major problem. We have come to a workaround arrangement with NDIA but at the end of the day a workaround arrangement indicates that their framework is incorrect. They come up with another item where they can say we will give you this but it doesn't actually acknowledge what we're talking about. Potentially every hour you offer a service you are losing money. We don't get paid to case manage so there is no case management because you don't get paid for it. We have two or three clients which nobody, including the state, will accept. Some of them have been three-to-one and we have been able to drop that to one-to-one through our organised activity areas. Now we are really clear in our minds why we are losing money, where we are losing it, what the paradigm shift needs to be from the NDIA or we will be going to them and saying we are the only provider who has been able to get things to work for these folk, you cannot actually pay us enough to cover our wages, so here they are back to you.*

One of the launch site lessons is that NDIA planners need strong links with providers to get funding packages right. But there were also particular concerns about covering the costs of services like respite and day activity especially where there were fixed overheads but no guarantee of participants. One organisation commented on the investment required to run day services and activities which they had developed over a number of years but where there was no acknowledgment of the intellectual property in NDIA pricing.

### 3.10 In summary

To conclude, supporting participants with behaviours of concern challenges services in a number of ways. The work required to maintain an appropriate environment and an appropriately skilled support team around the participant with behaviours of concern can be significantly higher than for other participants. This work translates into the additional time required to recruit, roster, train and support the support team as well as working with families and the input required from case managers, clinicians and managers to underpin these processes. In addition, unlike many other people with disabilities accessing services, it also requires a flexibility to respond to unanticipated and sudden changes in the level of support required and to deal with what are often volatile situations.

There is an understanding that significant investment in working with people with behaviours of concern can, over a period of time, increase a participant's quality of life and reduce behaviours and hence the work and cost involved in providing support. However if the additional work is not effectively managed the appropriateness of support and participants' satisfaction with the support can deteriorate and behaviours escalate. This in turn generates further work in terms of increased rates of incident reporting and their management, complaints and their investigation, property and vehicle damage, and risk to the morale of the workforce and the provider organisation's reputation.

There are questions about how the NDIS and the disability support market will respond to these issues in the longer term. Previously the additional pressures of working with people with behaviours of concern were spread between provider organisations by referral processes. Will choice and control now promote the creation of niche organisations and providers of last resort, will it promote cherry picking or will quotas to disperse those with behaviours of concern across a range of organisations be established? The answers to these questions and what those answers mean for supporting choice and control are as yet unknown.

# 4 COSTING THE UNCOUNTED COSTS

The prices used to construct individual funding packages for participants is a critical matter. Currently the NDIA sets the value for supports in participant packages and limits the price a provider may charge to that value (NDIA 2014). If a price is set too low providers will be unable to provide the choice or quality of supports that people need. If it is set too high the NDIS will not be financially sustainable. Setting a price involves a detailed understanding of the factors that contribute to service prices. As the NDIA and NDS have pointed out ideally this should be based on the independent collection of reliable data about cost so that prices reflect the actual cost to providers of delivering a range of supports.

Currently there are variations in prices between jurisdictions. The intention is to align these prices over time to create a single, national pricing template.

## 4.1 Reviewing NDIA prices

The NDIA has responded to concerns expressed by providers about pricing with a series of price reviews. In early 2014 the NDIA price list was revised in recognition of the additional costs generated by those with behaviours of concern and/or high medical support needs. Higher intensity complex support coordination was also recognised with a new and higher rate per hour.

Concerns continued to be expressed about hourly rates set for two of the highest volume supports – one-to-one support for assistance with self care activities and assistance to access the community. This led to the NDIA and NDS establishing a Pricing Joint Working Group (NDIA & NDS 2014) assisted by independent experts to examine these concerns and recommend solutions which would enable the introduction of a unit price or ‘efficient’ price that allowed providers to deliver the best outcomes to participants. Although this work did not result in agreement on price, it did result in a methodology for the reasonable cost model (RCM) or the methodology required to determine unit prices for these supports and transparency about price assumptions (NDIA 2014b). It also resulted in consideration of an interim pricing strategy or temporary ‘transition price’ to support providers, and the NDIA, as they transition from previous funding arrangements.

The Working Group also identified that a range of prices required further work and may require alternative funding arrangements. In relation to people with behaviours of concern this included individual high cost packages due to exceptional complexity. The Working Group recommended that this area should be explored including:

- improving the guidance to NDIA planners about who needs higher intensity support;
- improving guidance to NDIA planners about adequate hours for staff handover and the introduction of new support staff via shadow or buddy shifts for an agreed participant cohort; and
- funding appropriate service coordination in plans.

They concluded that access to improved cost data is essential to better inform price setting.

In Tasmania NDIA planners have expressed the view that exceptional clients will always require exceptional measures. This means that if evidence of additional uncounted costs for participants with behaviours of concern can be provided, then the NDIA can provide funding to cover these costs in individual funding packages on a case-by-case basis.

## 4.2 Case studies and uncounted costs

The efficient price (NDIA 2014) builds pricing assumptions from a combination of reasonable 'direct salary' plus 'program management and administration' plus 'corporate overhead' cost elements in a competitive market. Program management and administration costs include consideration of non-labour components some of which potentially cover elements of the uncounted costs.

**Table 2** Efficient Price (in 2014) – Assistance self-care and community support

<b>Drivers</b>	<b>Standard</b>	<b>High Intensity</b>
SACS	SACS 2.3	SACS 2.3
Direct Salary	\$21.30	\$21.30
Client facing time, including leave	85%	80%
Client facing time excluding leave	95%	90%
Supervision – Span of Control	1:18	1:18
Corporate Overhead	9%	9%
Return on Capital (margin)	5%	5%
<b>Key Costs</b>	<b>\$</b>	<b>\$</b>
Salary costs including client facing time	22.56	23.96
On costs	8.37	8.69
Corporate overhead	3.06	3.06
Return on Capital (margin)	1.78	1.87
Total per hour price	35.77	37.58
Add Jul 2014 indexation of 2.6% – total per hr price	36.70	38.56

From: NDIA 2014b

It is recognised that the efficient price will need to be assessed and reviewed against market experience and evidence about best practice and may require a loading framework to incorporate the additional costs of complexity. How does the efficient price as currently proposed match with what we know about the uncounted costs encountered in supporting those with behaviours of concern?

Table 3 itemises the estimated annual uncounted costs generated by supporting a range of people with behaviours of concern as demonstrated by our nine case studies (see Appendix 1 for costing methodology). It also estimates uncounted costs as a percentage of total annual support costs.

**Table 3** Case Studies: Annual Uncounted Support Costs in \$

<b>cases</b>	<b>property damage</b>	<b>vehicle damage</b>	<b>OH&amp;S incidents</b>	<b>workers compensation</b>	<b>consumables</b>	<b>travel</b>	<b>complaints</b>	<b>communications</b>	<b>recruitment</b>	<b>training</b>	<b>positive behaviour support</b>	<b>uncounted costs % total support costs</b>	<b>annual uncounted support costs</b>
<b>Very High Intensity</b>													
Tracey	4,774	4,184	5,096		7,602	4,825		4,476	7,395	5,120	34,288	32	<b>77,762</b>
Mary			2,548	3,540	500	2,875			7,395	5,120	34,288	20	<b>56,267</b>
Brett	6,000	1,000	3,058	3,540	2,344	4,825	9,590		14,790	5,120	34,288	34	<b>84,555</b>
<b>High Intensity</b>													
Jamie			2,548		500		2,500		5,546	3,075	7,638	29	<b>21,805</b>
Anthony		1,000	5,096		500	2,875			5,546	3,072	7,638	16	<b>25,728</b>
Sarah			2,548		500		5,996	14,394	5,546		2,648	37	<b>31,633</b>
<b>Stabilised/Cyclical</b>													
Sean			5,096		500	2,875			5,546	1,536	2,648	13	<b>18,202</b>
Jackie	1,500		1,019		500	2,875		2,346	5,546	1,536	2,648	11	<b>17,971</b>
Mathew			1,091		2,344	4,825			5,546	1,536	2,648	15	<b>17,919</b>
<b>Total in \$</b>	<b>12,274</b>	<b>6,184</b>	<b>28,030</b>	<b>7,080</b>	<b>15,289</b>	<b>25,975</b>	<b>18,086</b>	<b>21,216</b>	<b>62,859</b>	<b>26,114</b>	<b>128,733</b>	<b>23</b>	<b>351,841</b>

Note: Individual participants as described in case studies may be accessing a range of services including respite and day support from different organisations. This means that figures relate to the costs that might be encountered by Anglicare and Optia not to the total annual support costs for individual participants. These include:

**Property Damage:** Actual or estimate based on severity

**Motor Vehicle Damage:** Actual or estimate based on severity

**Incident and OHS monitoring:** Actual based on linked client

**Workers Compensation:** Average cost of incident payout (not WCOMP actual as refunded by insurer)

**Consumables:** Actual for severe client, estimates for other clients

**Travel:** Apportionment of motor vehicle costs + double-up of support worker where required

**Risk/complaints:** Cost of investigation as nominated by Optia

**Communications:** Additional communication required over and above case management hours nominated

**Recruitment:** Standard = 3, moderate 4, high 8

**Training:** Training hours beyond initial recruitment/induction

**Positive behaviour support:** Implementation, training and monitoring of client specific protocols

**Annual uncounted support costs:** Total of costs not in standard roster/weekly hours

Table 3 demonstrates:

- Uncounted costs at an average of 23% of total annual support costs. In three cases uncounted costs are more than 30% of total annual support costs. These uncounted support costs include training costs and behaviour support which can be itemised separately under the NDIA pricing model and included in the individual support plan. It is unclear however what percentage of the total price per hour of support is calculated to cover program management and administration under the efficient price model. This raises questions about the size of the gap between the allowance for program management and administration and real but uncounted support costs.
- High costs in areas like recruitment, complaints and incident management, communication and positive behaviour support. For example a restraining order might be taken out to ensure worker safety, or a participant or their personal networks may initiate excessive communication or formal complaints.
- A skew towards proportionally higher program management and administration costs for participants who have low direct care requirements, for example where they are receiving care at home instead of in a shared home environment (see Table 3: Sarah).
- Higher direct support costs for these participants due to higher costs in maintaining and administering rosters.
  - additional staff meetings required
  - higher care coordination costs including working with participants' families
  - higher rates of pay — Anglicare and Optia currently pay workers working with participants who require staff with high resilience and capacity to work successfully in complex situations higher than the Modern Award equivalents in order to attract and retain a skilled and motivated workforce, build autonomy and problem-solving in support teams and encourage career paths in this specialized area. These factors are especially pertinent when developing the capacity of a participant over a number of years. Both organisations also pay a higher rate for higher intensity support (SACS level 3) than the NDIA price for a worker with additional qualifications and experience.
- Concerns about the proposed 1:18 ratio for the span of control. This is considered to be unrealistic for participants with behaviours of concern.
- A lack of transparency about the workers compensation rate included in the reasonable cost model. Workers compensation insurance costs are correctly included within the on-costs of the direct service delivery. However participants with behaviours of concern have disproportionate rates of uncounted costs arising from incidents which require monitoring and management or minor costs which may be borne without resorting to reimbursement through a workers compensation claim. Behaviours of concern may also result in recurrent claims or lodging financially significant claims. This may negatively affect the annual premium with a significant impact on the provider organisation as a whole.

There are a number of additional uncounted costs which were incurred by the case studies which have not been costed in these tables due to difficulties in monitoring and estimating true costs. These include the costs generated by low staff morale, difficulties in delivering rostered support due to lack of participant engagement, non-rostered debriefing for support staff, participation of staff (including financial and administrative staff) in NDIA planning, review and transition processes and managing risk to the organisation's reputation. These costs are likely to be considerable.

### 4.3 In summary

What the table suggests is that the proposed pricing mechanism is currently unlikely to adequately recognise or allow for many of the identified costs and that program management and administration costs exceed the margin allowed for in the NDIA pricing methodology. As a result providers will be underfunded. These difficulties are accentuated when a participant with behaviours of concern has supports delivered by multiple providers. There is then a reasonable risk that their costs will be borne disproportionately by one or more providers.

There are currently two programmatic solutions to the gap between NDIA pricing and the real costs faced by provider organisations. The first is to apply additional hours, by way of direct supports, or possibly higher level supports (for example the 'behaviour support' cluster). These supports will be paid at whatever level is appropriate under the pricing template. However this is accompanied by an expectation that the direct supports must still be delivered; i.e. that there must be a sufficient volume of hours supplied by the provider bearing the indirect costs for that provider's indirect costs to be borne. This approach becomes particularly inappropriate when the participant has low direct care requirements but when uncounted costs are high. This was true for some of our case studies.

The second approach is to treat participants as 'exceptional' and allocate additional or 'exceptional' sums to cover high uncounted costs where providers are able to provide adequate evidence about their extent. This introduces a high risk for providers as the NDIS moves to the full scheme and to full cash operations. Providers run the risk of being out of pocket if the NDIA planning mechanism does not support their assessment or if the scheme is unable to pay providers in retrospect for costs incurred.

Although the costings as presented do not enable comprehensive benchmarking, they suggest that under the efficient price model as it stands provider organisations risk being inadequately funded to deliver the supports participants require because they are carrying high uncounted costs without any guarantee of funding to cover them. Without a detailed time and motion study which can measure the day-to-day complexities of supporting participants estimating a total price tag for both direct support and the range of currently uncounted costs is not possible. However the research suggests that applying the efficient price in its current form will put a severe strain on provider organisations working with people with behaviours of concern and hence on the ability of the market to provide choice and control to these participants.

# 5 CONCLUSIONS AND RECOMMENDATIONS

## 5.1 Conclusions

It has been said that ‘we should no more tolerate people being placed in inappropriate care settings than we would people receiving the wrong cancer treatment’ (DH 2012). The NDIA wishes to construct pricing mechanisms which are based on what we know about good practice in working effectively with participants who have behaviours of concern and in providing them with appropriate environments in which they can live their lives. There is also a larger question about whether individualised funding mechanisms can deliver a person-centred approach to supporting people with behaviour of concern and offer them choice and control where the key to effective working is relationships with support staff and a stable and consistent support team.

This report challenges the current pricing assumptions for supporting people with behaviours of concern. It suggests that the proposed ‘efficient price’ does not take into account a range of necessary and foreseeable costs. This may leave providers supporting a range of unfunded activities. This will have a significant impact on the ability to create a competitive disability support market for these participants where they are able to exercise choice and control over how their support needs are met. It will present particular challenges in Tasmania where there are fewer providers to deliver and especially when the participant is known to present significant challenges to services.

## 5.2 What is required?

We know that supporting people with behaviours of concern requires:

- Managing high indirect support costs which include property and vehicle damage, dealing with incidents and complaints, and additional recruitment and training costs.
- Flexibility in the intensity of the support delivered to cope with volatile situations which can change rapidly. This requires efficient support plan review mechanisms which can operate quickly. Having to follow complex procedures to amend funding packages when people’s needs change results in delays, additional costs being imposed on provider organisations and potentially the behaviour of participants escalating.
- Flexibility and room for creativity in funded support items to cope with very unique and individualised needs and new types of support that might be outside the normal scope.
- Skilled and experienced support teams where there has been an investment in training.
- Working with participants’ families to develop positive working relationships.
- Recognition of the need for ongoing expert clinical support which can address the causes of behaviours of concern and skill up support teams to manage it in effective ways.
- A no blame culture through a general recognition of what is entailed in supporting those with behaviours of concern. This requires respect for the expertise of providers and their knowledge of individuals rather than an assumption that an organisation has failed.
- Up front investment to provide whatever support is necessary to make a service work and derive positive outcomes, for example in establishing appropriate support teams and behavioural protocols. This requires a recognition that it may take a number of years before costs reduce and situations stabilise and means not

imposing arbitrary maximum costs on services.

- Involvement of providers in NDIA planning processes.
- Investment in ongoing research, development and training to further develop evidence based best practice approaches and a workforce skilled in implementation.

Organisations supporting people with behaviours of concern require the ability to work in this way. The way in which NDIA pricing, processes and planning mechanisms work therefore need to be able to support this ability.

## 5.3 Recommendations

The following recommendations have grown out of the research and support current developments in improving NDIS pricing mechanisms prior to moving to full scheme.

**Recommendation 1**      **That mechanisms for an ongoing dialogue between service providers and NDIA planners and administration be fostered and promoted.**

There are sound reasons why the voice of service providers has been muted during the development and trialling of the NDIS. However it is also clear that if a strong disability support market is to develop for the benefit of participants the realities of delivering services on the ground need to be understood and incorporated into the way in which the NDIS develops, particularly as it moves towards full scheme. This requires sustainable mechanisms to foster the dialogue and ensure that it is ongoing. One approach might be for NDIA to convene an advisory panel of providers or for providers to initiate a community of practice to identify best practice in supporting participants with behaviours of concern.

The report raises concerns about potentially significant uncounted costs which arise in delivering supports to people with behaviours of concern. Many of these costs have not been incorporated into the current reasonable cost model raising the risk of providers being underfunded. If the support they provide is unsustainable it will threaten any choice and control participants might have in the disability support marketplace. In order to address these issues we make a number of recommendations about clarifying the kind of participants who generate uncounted costs and how they should be identified during the NDIA planning process, ensuring costings are accurate and introducing more flexibility in funding mechanisms which can respond to volatile situations.

**Recommendation 2**      **That NDS/NDIA undertake a detailed time and motion study to fully assess what is involved in providing support to participants with behaviours of concern.**

This research did not have the resources available to provide comprehensive benchmarking for costs which are currently uncounted. In order to fill this information gap there is a need to conduct a full time and motion study among a number of different providers over a 12 month period to fully assess exactly what is required to support a range of participants who might be described as having behaviours of concern. This study should sample participants across a range of communities including urban, rural/remote and CALD communities. This will provide an evidence base and an accurate estimation of costs which can then be incorporated into costing structures. This exercise should be overseen by NDS who would be funded to undertake the work with representation from the advisory group/community of practice identified in recommendation 1.

**Recommendation 3**      **That the reasonable cost model incorporate a ‘higher intensity plus rate’ for participants with behaviours of concern.**

In order to cover uncounted costs participants with behaviours of concern require support over and above that provided through the current higher intensity support rate.

**Recommendation 4** That a template be developed for providers and planners to raise awareness about the criteria for attracting the 'higher intensity plus rate' and complex care coordination in order to better assess individual funding packages.

A key issue is how far NDIA planners are able to recognise participants who should attract the higher intensity plus rate and/or who require complex care coordination. This is particularly true for participants who have low direct support needs but nevertheless generate a high impact on support staff and provider organisations and where a considerable amount of work is required to make direct support packages viable. Service providers have also commented on the time involved in participating in NDIA planning processes, in providing quotes for support and on the difficulties of negotiating reviews of individual packages as new support needs come to light. A set of criteria for entry to the higher intensity plus rate and a template to frame the planning process which itemises potential uncounted costs would raise the awareness of planners and smooth the planning process. This could be accompanied by an NDIA developed Report Card at three months to review the situation and flag any difficulties. One approach is for providers to develop criteria in partnership with NDIA representatives which are then endorsed by the advisory panel/community of practice identified in recommendation 1.

**Recommendation 5** That providers have access to a contingency or 'brokerage' fund which can be used to contain situations in the shorter term.

**Recommendation 6** That block funding/bulk purchasing be available to enable investment in capacity and innovative approaches, for example in accommodation options, prior to the completion of the NDIA planning process.

As the research demonstrates participants with behaviours of concern can be volatile and situations can change quickly and require speedy responses. Recommendation 4 will assist with speeding up review and planning processes in order to deal with these situations. However there is also a need to have access to additional funds outside individual support packages to cope with complex, crisis and emergency situations, to bring them under control, prevent them from escalating and provide wraparound support whilst assessments and reviews are undertaken. Any funding should also cover the ability to evaluate outcomes in terms of quality of life and participation in the community.

**Recommendation 7** That providers working with participants with behaviours of concern be able to consider the option of salaried support workers to provide higher quality support.

In some parts of Tasmania there have been considerable difficulties in recruiting support workers to work with participants with behaviours of concern. There is currently much work being done nationally to sustain an adequate workforce to deliver the NDIS. One option to both improve recruitment and professionalise working at this end of the spectrum is to offer workers annual salaries. This would also have the benefit of potentially improving the consistency, skills and experience of support teams which can be so important in working with these participants.

**Recommendation 8** That care coordination should be provided by the primary support provider when supporting participants with behaviours of concern.

Lastly the research clearly demonstrated the difficulties which can be encountered when the care coordination function is separated from the primary support provider particularly when trying to resolve crisis situations, pro-active day-to-day and preventative work and the role modelling of good practice. The research makes a strong case for the primary support provider to also undertake the care coordination work in order to maintain supports and achieve desired outcomes.

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# APPENDIX 1: METHODOLOGY FOR COSTING FICTIONAL CASE STUDIES

The process of costing fictional case studies has been based on:

- Linking specific characteristics of case studies to actual existing clients where possible– for example rostering workloads, number and investigation of incidents;
- Estimating additional staff hours involved in investigating incidents or complaints, attending extra staff meetings and translating this cost into payroll cost, on cost (eg superannuation) and overhead (eg rent) allocations as applicable;
- Monitoring work undertaken by both Anglicare and Optia to explore the actual costs of challenging clients in specific areas. These include staff recruitment, management of complaints, in-house clinical support with behavioural interventions and their implementation; and
- Estimating cost through Anglicare’s accounting processes in order to reduce the resources required for costing by processing it through both Anglicare and Optia finance departments.

This methodology excludes the costs generated by:

- Low staff morale and how this might impact on productivity and quality of care;
- Non rostered debriefing time;
- Lack of engagement – where rostered support cannot be delivered;
- The participation of staff in NDIS planning and review processes including an increased load on financial and administrative staff for claim lodgement and the transition of existing clients into the NDIS framework;
- Managing risk to the organisation’s reputation; and
- Managing the risks associated with workplace health and safety incidents and workers compensation claims.

## Direct wage costs

### Personal support costs

- Wages specific to the client, assuming payment under Anglicare’s collective agreement rates for direct support work. These rates are slightly higher than Modern Award equivalents, but are not unreasonable in the competitive marketplace.
- Additional supervision for community access calculated as 5 hours a week at support worker rate (including on-costs) where the client requires a higher level of support.
- On costs were calculated as:

Annual Leave %	Super %	Workers Comp %	Long Service Leave	Sick Leave
11.30	9.50	2.50	2.50	3.85

Annual leave is 5 weeks per annum (allowing for an additional week’s leave due to 24x7 rostering effects) multiplied by leave loading of 17.5%.

Superannuation is 9.5% per existing legislative requirement.

Long Service Leave is 13 weeks after 10 years of service, or 13/520 weeks.

Sick leave is 2 weeks per annum.

### House or facility roster costs

- Wages are apportioned as part of a standard roster for a shared home for 4 clients with relatively high needs. This includes sleepovers, but excludes individual requirements for community access, educational support etc. which are noted in the above supports.

## Staff meetings or meetings

- Taking one quarter of meeting costs per week for an existing shared home with 4 clients with relatively high needs. This was loaded at 120% or 110% for higher needs client(s) as required and loaded at 90% of remaining clients.

## Rostering – cost of administering roster by client

- 12 month one-off and permanent shift change data for similar AT HOME clients. Where not individually defined, as per average of broad cluster of clients.
- Wages paid under Anglicare’s collective agreement rates for workforce co-ordination team, + on-costs (as per support workers) + office overhead allocations for rent, ICT etc.

## Other client costs

### Communication

- Additional communication required over and above staff support time nominated.
- Includes case manager, support worker, workforce scheduling and reception/inbound call centre time.

### Consumables

- Relates to cleaning supplies and cleaning services. Continence aids etc. are assumed to be funded directly by clients and/or NDIA supports identified in the care plan.
- Actual for high intensity client, 30% of high intensity for two other identified clients and estimated for remaining clients.

### Travel and transport

- Standardised motor vehicle cost of \$11,500 including depreciation and foregone interest (i.e. lease equivalent) costs, fuel, maintenance, registration etc. 25% of standardised costs applied to each client at a group home or cluster as a proxy for regular usage required.
- Additional motor vehicle kilometre costs assumed as 50 kilometres per week at the Modern Award rate of 76c.
- Other travel is assumed to be funded directly by clients and/or NDIA supports identified in the care plan.

### Property damage and motor vehicle damage

- Actual for identified cases in each area and estimates based on severity for others.

## Program management and administrative costs

### Case management

- Wage costs as per Anglicare’s collective agreement for case management positions + on costs (as per support workers) + office overhead allocations for rent, ICT etc. + motor vehicle/travel costs.
- Total costs /1976 hours per annum derives a nominal hourly cost.
- Time as advised by state manager for case management time allocations by client, linked to existing clients.

### Incident and OH&S monitoring

- Wage costs as negotiated for Workplace Health & Safety positions + on costs (as per support workers) + office overhead allocations for rent, ICT etc. + motor vehicle/travel costs as applicable.
- Total cost /incidents per annum derives a cost per incident monitored.

## Workers Compensation

- Insurance premiums are included in wages as an on-cost.
- Workers compensation actual costs are refunded by the workers compensation insurer, therefore not included as a cost.
- However, minor incidents occur that result in costs paid 'without prejudice', which have been flagged. These have been costed at the average of minor incident claim costs paid over a 2 year period for the selected client group + an instance of 'incident monitoring' as above.
- Workers compensation premiums change annually as a result of risk management measures implemented and claims lodged. A higher needs client where there are recurrent claims or financially significant claims may negatively affect the premium paid with a significant impact on the organisations as a whole.

## Risk/complaints

- Hours calculated for known instances of complaint management.
- Wage costs as negotiated for senior and executive management positions + on costs (as per support workers) + office overhead allocations for rent, ICT etc. + motor vehicle/travel costs.
- Total costs /1976 hours per annum derives a nominal hourly cost.
- Legal costs associated with ensuring worker safety (arising from interactions with the client's support network).

## Recruitment

- Calculated at three levels – standard, moderate and high (3, 4 and 8), based on employee turnover data from client sample over a 2 year period. Sample clients were selected on the basis of being identified as high needs.
- Recruitment costs include pre-employment medical plus initial training (First Aid, Medication and Manual Handling) external costs + 35 hours of attendance at initial training or induction, costed at personal support wage rates as above.

## Training (including participant-specific training)

- Ongoing training hours required beyond initial recruitment/induction. These hours are in part induction relating to a specific client's needs, or ongoing in relation to the in-house training.

## Positive Behaviour Support – in-house participant-specific training and oversight

- Wage costs as negotiated for Anglicare's Practice Support Unit positions + on costs (as per support workers) + office overhead allocations for rent, ICT etc. + motor vehicle/travel costs.
- Hours as advised by Anglicare's Practice Support Unit relating to annual costs for high, medium or low needs clients.

## Organisational overheads @ 14% of total costs

- It is noted that a KPMG assumption of 15% was applied in the Tasmanian Unit Pricing Methodology. This organisational overhead cost included a risk/continuity of business premium.

## Find out more

SARC, the Social Action and Research Centre at Anglicare Tasmania undertakes research, policy, advocacy and social action to achieve positive social change.

You can learn more about SARC's work, read research and policy documents or find further information at:

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