

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

Implementing the National Disability Insurance Scheme

This study explores how the National Disability Insurance Scheme (NDIS) can best ensure that people with behaviours of concern are offered choice and control in the emerging disability support market. It was undertaken by the Social Action and Research Centre at Anglicare Tasmania during 2014. Using the experiences of two provider organisations - Anglicare and Optia - the research examines what is involved in providing support for people with behaviours of concern and how this experience can be considered within the NDIS. This summary outlines the main findings and recommendations.

People get burnt out a lot more quickly because it takes a lot more out of you. They are very challenging 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 people you might have the same staff going there for 10 years.

What are behaviours of concern?

People with behaviours of concern are a very diverse group. They include those with learning disability and cognitive issues, different sensory or physical impairments, mental health, communication and personal relationship issues, co-morbidity, acquired brain injury and autism. Some may engage in behaviours that put themselves or others at risk. They can demonstrate verbal or physical aggression, damage property and vehicles and have self injurious behaviour. Their needs can be unpredictable and their capacity to indicate their preferences limited. The term 'behaviours of concern' is intended to emphasise that challenges for services in providing support are often caused as much by environmental factors and the way in which a person is supported as by their own characteristics (DH 2007).

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 about 50 people who would fall into this category in Tasmania.

The Research

The study explored in microcosm what is involved in meeting the support needs of participants with behaviours of concern. It involved:

- identifying current participants in Anglicare and Optia with behaviours of concern;
- talking to care coordinators about the challenges of supporting them and the uncounted costs;
- compiling nine case studies representing the range of issues and support needs and calculating the uncounted costs; and
- developing a set of recommendations to ensure that uncounted costs are incorporated into funding allocations.

When you have a high turnover it means you are continually having to buddy in 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...

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.

The Issues

The NDIS puts people with a disability and their families at the centre. Participants 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 a National Disability Insurance Agency (NDIA) planner based on their individual support needs, goals and aspirations. However unless true costs are reflected in NDIA price setting the emergence of a disability support market risks:

- introducing market incentives to ‘cherry pick’ those participants who require low level supports, are easy to manage and where staff require no particular qualifications;
- failing to guarantee services for particularly vulnerable participants leading to under-servicing and unmet need or to local monopolies which may overcharge;
- being unable to guarantee a safety net if the support system around those with behaviours of concern collapses;
- threatening 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
- failing to provide a broad range of services from which participants with behaviours of concern can choose.

These risks may be reflected in higher charges, poorer outcomes and a lower quality of life for those with behaviours of concern whilst, at the same time, eradicating their choice and control.

Key Finding 1

The research found that the work required to maintain an appropriate environment and support team around people with behaviours of concern can be significantly greater than for other participants. 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 receive 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.

To work with someone like that you need to have knowledge behind you about 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.

Key Finding 2

Higher costs were attached to:

- **direct support** due to increased costs in maintaining and administering rosters, the additional staff meetings required and higher care coordination costs including working with participants' families. Anglicare and Optia also pay staff working with these participants more than the Modern Award equivalents in order to attract and retain those with high resilience and a capacity to work successfully in complex situations, build autonomy and problem-solving in support teams and encourage career paths in this specialized area.
- **program management and administration** 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. Although training costs and behaviour support can be itemised separately under the NDIA pricing model, it is unclear what percentage of the total price per hour of support is calculated to cover program management and administration. There is also a skew towards proportionally higher program management and administration costs for participants who have low direct support requirements. The case studies estimated uncounted costs at an average of 23% of total annual support costs. In three cases uncounted costs were more than 30% of total annual support costs.
- **additional uncounted 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.

Key Finding 3

As well as managing high uncounted costs supporting people with behaviours of concern requires:

- flexibility in the intensity of the support delivered to cope with volatile situations which can change rapidly;
- 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;
- 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;
- involvement of providers in NDIA planning processes; and
- investment in ongoing research, development and training to further develop evidence based best practice approaches and a workforce skilled in implementation.

Key Finding 4

The 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. To this end they have responded to concerns expressed by providers about pricing with a series of price reviews and the development of the Reasonable Cost Model (RCM), or the methodology required to determine unit prices for supports and transparency about price assumptions (NDIA 2014b). There has also been a push towards more guidance for NDIA planners about what constitutes high intensity support needs including the additional costs associated with sustaining support teams for those with behaviours of concern.

However the research demonstrates that significant necessary and foreseeable uncounted costs remain and would not necessarily be met under the current RCM or efficient price model. 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.

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. 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.

Anglicare and Optia Recommend

1. Research and information

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

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

2. Recognition of higher costs

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

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.

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

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.

3. Practice

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

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

References

Department of Health 2007, *Services for people with learning disabilities and challenging behaviour or mental health needs*, revised edition (ed. J Mansell), United Kingdom.

McLean, I 2012, *Providing choice in the new world for people who exhibit severe challenging behaviour (at times)*, presentation to NDS Conference, *Preparing for the New World Conference 2012*, Adelaide.

National Disability Insurance Agency (NDIA) 2014b, *NDIA report on the methodology of the efficient price*. NDIA.

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.

For more information

The full report *The Uncounted Costs: Choice and Control for People with Challenging Behaviours* by Teresa Hinton, is published by the Social Action and Research Centre at Anglicare Tasmania and Optia Inc

It is available by calling 1800 243 232 It can be downloaded at www.anglicare-tas.org.au/research

Social Action and Research Centre (SARC)

Anglicare's SARC team works with low income Tasmanians to identify the structural barriers that impact most severely on their lives. The Centre pursues policy changes on these issues at a State and Federal level.

