

Goldfields Individual & Family Support Association Inc.



Productivity Commission

Submission

Review of the National Disability Insurance Scheme Costs

22 March 2017

BACKGROUND:



GIFSA is a significant regional community development not-for-profit (NFP) benevolent organisation employing 119 local people and supports over 250 people with disability, their families and carers.

GIFSA's operational area covers the vast 771,000km² Goldfields-Esperance region of WA. Within the region there are three distinct sub-regions, The Lands, Goldfields and Esperance (see diagram above).

The Goldfields-Esperance region is unique in that it is three times the size of Victoria, 2.4 times the size of the Barkly (NT) region and with a population of only 65,000 people.

As the only regionally headquartered Disability Service Organisation that covers the entire region, the communities it services are intrinsically connected to the organisation.

Providing services to people with disability in such a large region, within the bounds of the of Australis's largest State or Territory, needs to be better appreciated and considered and the costs of service delivery better understood and funded appropriately. A one-fit-all approach will not meet the needs of participants and service providers.

It is in this context that the NDIS will have many challenges that will require special consideration particularly in a thin market over such large distances.

GIFSA participated in the WA Disability Service Commission's My Way initiative however was not a NDIS trial site. The Disability Services Commission has advised the sector that the Goldfields-Esperance region is expected to roll into the NDIS effective 01 July 2018.

GIFSA's submission attempts to address key elements of the Terms of Reference that include:

- the sustainability of scheme costs, including current and future cost pressures, and how to manage any potential cost overruns
- whether jurisdictions have the capacity to deliver disability care and support services as the scheme expands
- how the NDIS impacts on, and interacts with, mainstream services
- whether efficiencies have been achieved within the scheme
- whether there are any issues with scheme design, including the application of market and insurance principles, in ensuring the best possible outcomes for people with profound or severe permanent disability
- funding and governance arrangements, including financial contributions, risk-sharing, and the 'escalation parameters', which define the annual increase in funding required by different jurisdictions,
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GIFSA'S POSITION:

- GIFSA strongly supports a decentralised and localised WA state governance model.
- GIFSA supports a payment system that ensures Disability Service Organisations are paid in advance rather than in arrears.
- GIFSA is concerned that should the NDIS fail to meet the heightened expectations of regional communities, particularly remote and very remote locations, the political repercussions could be damaging to the Government and the responsible agencies.

- Not-for-profit organisations like GIFSA have for some time enjoyed the protection of the State Government’s Delivering Community Services in Partnership Policy (2011) and the Non-Government Human Services Sector Indexation Policy. It appears that, at this point in time, little is understood as to the State Government’s position on these two policy settings leading up to the NDIS implementation. It is important for regional Disability Service Organisations, most of them NFPs, to know what the State Government ongoing support might look like and therefore clarity is sought.
- In GIFSA’s experience thus far, real “**Choice & Control**” is diminished by budget constraints. Moreover, “**reasonable and necessary**” supports will also be subject to budget constraints. Once again, the expectations of People with Disability may well be compromised when the NDIS is introduced. For example the average NDIS package in this region will far exceed the average package set by the NDIA.
- There appears to be little knowledge and understanding around the possible “collateral damage” resulting from the NDIS, be it Disability Service Organisations or People with Disability, their families and carers. The hype and excitement around the NDIS appears to drown out real concerns and constructive criticism of the Scheme, particularly in the regional setting.
- GIFSA acknowledges the intention of Information, Linkages and Capacity Building (ILC) and funding thereof as part of the NDIS that is intended to build the capacity of the broader community to support and involve people with disability. We also acknowledge that ILC is not tied to individualised NDIS support packages. It appears that ILC is significantly underfunded and therefore will not deliver on rising community expectations.
- GIFSA expects there will be a need for increased number of planners within the new governance model. Attracting and retaining suitable planners will be a constant challenge in this region given that the labour market fluctuates wildly depending on the fortunes of the Mining Industry. We make the following observations:
 - Evidence from existing NDIS trial sites may not reflect accurately the needs of this region.
 - The tyranny of time and distance within this vast region will impact and test the planning processes.
 - Recruiting suitable/competent planners has always been and will continue to be problematic and challenging

- Planning for people in remote and very remote locations will be very challenging, costly and, in many instances, insurmountable.
 - GIFSA is, and always has been, well placed to support the planning process.
 - Aboriginal people in this region are and will continue to be resistant to any externally imposed planning process i.e. they are a highly mobile culture and not inclined to respond to “white fellas” planning rules. Moreover they find adaptation to change very difficult and are dependent on one/one in-person relationships. The top-down approach from Government, and compliance thereof, is generally not well received, understood and therefore problematic.
- In GIFSA’s view insufficient attention has, to date, been given to the unique challenges of disability service provision in remote and very remote settings. Particular challenges will be transport and accommodation that we believe are problematic, and for a range of reasons, including cultural reasons, individual funding may well be unworkable. These two particular issues were the subject of some discussion at the 2016 NDIS Remote Providers Forum in Adelaide and continue to occupy the thinking of the GIFSA Board. It seems clear to GIFSA that such matters may not be well understood and greater focus should be directed to remote and very remote Western Australia and the particular challenges faced by individuals experiencing disability in developing service plans as provided for under NDIS arrangements. GIFSA takes the strong view that transport ought to be funded separately and not included as part of participant support hours. Furthermore, we take the view that block funding for remote locations/ communities is vital because trying to attach dollars and deliver outcomes to individuals in these locations is extremely challenging one to one.

Case Study

Issues specific to the application of the NDIS to remote Aboriginal communities on Ngaanyatjarra (NG) Lands.



“Choice of service provider” and gaps in service provision

GIFSA has a staff member living on the Ngaanyatjarra Lands who covers six communities; Warburton, Jameson (Mantamaru), Blackstone (Papulungkata), Wingellina (Irruntju), Warakurna and Wanarn. The funding description for this employee is to provide day respite to carers of people with mental illness and intellectual disability.

The other services in this region that provide support to people with disabilities and their families are; PHAMS. Ng Health and NPY Women’s Council.

PHAMS provides mentorship and support to people with a mental health condition in Warburton only. This initiative has had problems maintaining its service over the years with staffing and reporting problems. It is currently operating minimally while attempts are made to re-staff and get the service running effectively again.

Ng Health runs medical clinics and had a mental health nurse but this position is now unstaffed. Nurse practitioners provide general medical care and crisis management that includes flying people out with the Royal Flying Doctor Service (RFDS) in cases of emergency. The RFDS responds to emergencies across Western Australia and Northern Territory as they are able, usually between seven and fourteen hours after notification. Currently these communities have been without a doctor for several weeks and a visiting doctor is not due for another couple of months.

NPY Women’s Council has an employee stationed at Wingellina. That person covers the communities of Wingellina, Blackstone, Jameson and Warburton. There is another NPY employee who is based in Alice Springs who covers the communities north of the Great Central Road. Their brief is to provide case management to clients with a physical disability. In some circumstances they may be able to provide limited assistance to clients with mental illness.

Generally, they work with clients and arrange respite in Alice Springs while our coordinator works with the supporting carers (or families) and provide respite on the Lands. There are occasions when there is some limited cross-over of service provision.

Furthermore, there are notable gaps in provision of services. For example one woman, who had suffered multiple premature strokes, found it difficult to get service support from anyone in that it was determined that she was ineligible for disability or mental health supports. Thus, she fell between the cracks and, with few agencies and limited services, found herself unsupported until a crisis occurred and she was removed to a locked ward of a dementia unit in Perth; a wholly unsatisfactory and inappropriate solution.

Other obvious gaps are that GIFSA is funded to provide respite to carers of people with mental health and intellectual disability, while NPY provides service to the actual client with either a physical or intellectual disability. Thus, respite services are not readily available to carers of people with a physical disability and with the exception of Warburton PHAMS when it is active, services are not readily available directly to people with mental health issues.

Tyranny of distance and time

It is two hundred kilometres from Warburton to Wingellina and one hundred and seventy kilometres by road from Jameson to Warakurna. The six communities serviced fit in a box approximately 34,000 kms². All roads are unsealed.

Furthermore, the communities cross two time zones. In order to make an 8am appointment in Blackstone, the employee must leave at 5am from Jameson even though Blackstone is only a one hour drive. Conversely, it is possible to arrive home in Jameson an hour before you have left Blackstone. The time zones are further complicated by the fact that the time differences change over the year as different zones move in and out of daylight saving, or not.

Added to this is the planning that must go into ensuring that the vehicle has enough fuel. Different stores in different communities have different and often restricted opening times, not just with respect to their time zones but also idiosyncratic to their community. As running out of diesel on these long isolated desert roads could lead to a disastrous situation, the employee must always plan to be able to purchase fuel in between respite trips and time trips and service to clients around availability of fuel. Almost all of the stores are closed on Wednesday afternoons and Sundays. It is possible, to be trapped in a community over the weekend, or overnight due to store closures and due to limited accommodation, also to have nowhere to stay. These considerations often lead to long days even if there are only a few hours of actual client contact.

NPY has its head office in Alice Springs and GIFSA has its office in Kalgoorlie-Boulder. Kalgoorlie-Boulder is approximately one thousand kilometres south-west of Warburton and Alice Springs is roughly the same distance north-east. In order to provide respite at facilities in these two towns and to attend training courses, respite coordinators must drive these distances on mostly unsealed roads.

Delivering training on the Lands is challenging in terms of the reliability of technology, using the distributive learning model, or the costs associated with delivering in-person training i.e. transport and accommodation are either not available or cost prohibitive.

As the respite worker must cover vast distances to maintain contact with clients, the employee must travel to the community for which service is being provided from the community that is their home. Usually, due to the distances, the employee will need to pay for some accommodation in the community for a few days. The employee will then have to walk and drive around the community, locating clients and determining their needs and availability. This will usually take about two days. The employee will then have two working days to take people out on respite trips, spend time on advocacy and advice issues and then one day returning from the community to their home community. Some time needs to be allocated to administration, vehicle maintenance and meeting the reporting provisions.

When a community is relatively close, seventy or eighty kilometres away, it can be more feasible to drive as a day trip. Yarnangu are still very mobile and move around communities as opportunities present. On one occasion, the respite worker drove eighty kilometres to Blackstone to fulfil a prearranged commitment to clients to take them out for a day trip. On arrival, the community was completely empty. All clients and community members had left without notice early that morning to attend a football event across the border in South Australia.

Respect for cultural differences

Yarnangu people value relationships over service. They simply will not work with someone they do not like or with whom they do not feel a connection. Thus, they regard workers as either personal friends or they avoid them. This leads to a blurring of public and private space. They do not understand that a worker has “finished work” because they see the worker as a personal friend who cares for them in a personal or family way.

This leads to situations where clients will come to the door at all hours of the day and night for assistance. Workers on the Lands find that if they try to set firm time boundaries, these will be ignored. A great deal of energy can be fruitlessly expended simply attempting to turn away persistent clients. This exercise can be exhausting and time consuming and often leads to confusion and anger in the

client. If the employee succeeds in setting the boundaries, the client will feel personally hurt and rebuffed and will tend to avoid the service.

Clients also will come to the door on weekends expecting to be taken out. They do not see it as work for coordinators but as a social event. Workers on the Lands work most effectively if they are prepared to be flexible and work when people approach them. It can make the working week very unpredictable. It is not unusual to work every day for several weeks and then to have a big gap because people have gone away to another place for a funeral or the football.

“In order to be a productive respite worker and an effective advocate, a worker must recognize this cultural need for personal connection and allow personal relationships to form”

These demands will always fall on a worker who resides on the Lands and the only way to remain effective in the job and avoid burnout is not to struggle against it but for workers to have adequate time/holidays completely out of the field where clients are not coming to the door at all hours. .

Yarnangu who live on the Lands have considerable difficulty negotiating whitefella bureaucracy. English is a second language for them and discussing important issues in English tires them and often leads to misunderstandings. In the absence of suitable language skills ***The Government ought to consider funding translators***. This problem is exaggerated for those who have a disabled or mentally ill family member and who have a pressing need to deal with a myriad of services.

Many are unaware of services they are eligible for and they become frustrated with the red tape and dealing with departmental officers who are strangers and often seem unsympathetic to them. Advocacy is a big part of what GIFSA and NPY provide on the Lands and this is only effective when yarnangu have built up relationships of trust over a long period of time.

GIFSA has two client families, each have a profoundly physically and intellectually disabled child whose needs cannot be catered to on the Lands. The families wanted their children taken care of in a city, such as Perth or Alice Springs where the children could have their needs met in ways that are not possible on the Lands. Both families approached the Department of Child Protection asking for help, preferably in having the children fostered out without losing their parental rights. DCP took the position that as neither family showed

evidence of neglect or abuse towards their children and they would not offer any support. Disability Services could not offer support for rehousing the children. GIFSA has been heavily involved in supporting these families and helping them to map out viable options in order to find the best and most workable solutions.

These desperate families came to GIFSA because they have a good relationship with the Lands employee who they see as a personal friend.

Another cultural issue is transience. Yarnangu are still a very mobile population. GIFSA currently has 58 clients on our active list and a further 23 clients who are currently inactive because either they or their carers have cycled out of the service area. At any time, many clients and/or their carers are moving between communities and may be out of the service area while others are moving back in. It is impossible to predict over any six month period how many clients will be eligible for service either because they are in/out of the service area, or their carers are in/out of the area.

Staffing

Due to the geographical distances involved, staff who provide these services to yarnangu must live on the Lands. At this point in time staff who are both suitably qualified and also reliable who are indigenous to the region are lacking. Qualified and suitable staff must be brought in from outside. Their housing and transport costs are quite high. The working conditions are demanding and unique. People who are not indigenous to the region are not permitted to stay nor can they be offered housing under the provisions of the Native Title Act, once their employment ceases to be permanent. Although there is scope for indigenous employment to be developed over time, currently there is no pool of qualified workers who can be employed on a casual basis.

The cost of living is high for whitefella workers. Fuel is expensive (\$2.06 diesel per litre but necessary as the distances are great and there are no alternative methods of transport. Food is expensive, limited and not fresh, transported in refrigerated trucks every couple of weeks from Perth. There is no pool of private housing available and the housing on the Land can only be leased to organisations providing services.

As discussed in the beginning of this submission, services often fail or are severely limited due to unreliability of employees, both indigenous and whitefella; indigenous because of a different value system and whitefellas due to the severity and demands of the working conditions.

Finally, staff in related fields such as Ng Health, often call on the GIFSA employee for help due to the quality of the worker's relationship to patients and the worker's knowledge and access to resources. Recently some community members came to the door late at night because one of GIFSA's clients, who is a

mental health patient and known to be violent, had suffered a seizure. They needed medical assistance but were nervous about approaching the medical staff out of hours. GIFSA's employee contacted the nursing staff who requested that she attend with them for safety reasons and because she knew the family and the situation. GIFSA's employee has continued to assist the staff to investigate long-term solutions for this patient. Staff must go out of their way to support staff from other organisations here because qualified and essential people often leave due to feeling unsupported by their own organisations or the lack of services. This is another demand on workers

Summary

Moving from block funding to retrospective payment on a per service basis will fail on the Lands for the following reason:

Costs and economies of scale: Any service provider must cover the following costs for a worker on the Lands -

- Full-time wages as workers cannot be employed casually for reasons stated above and also considerable time is spent by workers driving vast distances, locating clients, building quality client relationships and working behind the scenes in advocacy
- Housing for a Lands based worker as travelling in and out of a major population centre on a daily basis is geographically impossible
- Exceedingly high fuel and vehicle costs incurred to fulfil service obligations
- Office time meeting extra reporting standards that are outside of face-to-face interactions
- Infrastructure in head offices that must be maintained to support workers in remote areas
- Planning ability; Organisations must know in advance what money they have to support disability projects in remote locations. Housing must be paid for, leases signed, four wheel drives purchased and maintained etc.

The reality for service provision in remote locations is that there is a paucity of services and the services that do exist often fall over due to lack of support and insufficient funding. Clearly, support services remote and very remote locations stand to save the government considerable money in the long term.

In the case of the high needs children with severe physical and intellectual disabilities, the costs of full-time supported care in city based facilities is hundreds of thousands of dollars for each child per year. The longer that families can be supported in their caring roles, the greater the reduction of cost to the public purse. As expensive as block funding is perceived to be, it is cheaper by far than reducing disability support services to remote indigenous communities.

The likely result of losing block funding will be an almost complete loss of such services on the very remote Lands.

The Goldfields-Esperance region of Western Australia is indeed unique and, notwithstanding the merits of a federated NDIS model, there are particular challenges in remote and very remote Australia that clearly need particular funding consideration.

We hope this submission highlights some of those issues and paints a picture for the Productivity Commission that accurately reflects the lived reality of delivering quality disability services in a challenging environment.

Thank you for the opportunity.

Graham Thomson
Chairman

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