

## Carer and service providers' experiences of individual funding models for children with a disability in rural and remote areas

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### What is known about the topic

- IF is increasingly favoured by governments globally.
- IF has the potential to empower service users with more choice and access to new opportunities.
- People with a disability living in rural and remote areas have fewer service choices on which to spend their IF.

### What this paper adds

- Highlights the issues related to accessing IF in a rural and remote area.
- Identifies benefits and barriers for rural and remote service users and service providers using IF models.
- Suggests strategies for enhancing the experience of IF for service users and providers in rural and remote areas.

### Abstract

There is a global movement for people with a disability towards person-centred practices with opportunities for self-determination and choice. Person-centred approaches may involve individual funding (IF) for the purchase of required support. A shift to a person-centred model and IF should allow people with a disability and their carers greater choice in therapy access. However, individuals who live in rural and remote areas have less choice and access to therapy services than their metropolitan counterparts. Drawing on data from a larger study into therapy service delivery in a rural and remote area of New South Wales, Australia, this study describes some benefits and barriers to using IF to access therapy services in rural areas. Ten carers and 60 service providers participated in audio-recorded focus groups and individual interviews during which IF was discussed. Transcribed data were analysed using thematic analysis and constant comparison. Greater access to and choice of therapy providers were identified as benefits of IF. Four barriers were identified: (i) lack of information and advice; (ii) limited local service options and capacity; (iii) higher costs and fewer services and (iv) complexity of self-managing packages. A range of strategies is required to address the barriers to using IF in rural and remote areas. Carers indicated a need for: accessible information; a local contact person for support and guidance; adequate financial compensation to offset additional travel expenses and coordinated eligibility and accountability systems. Service providers required: coordinated cross-sector approaches; local workforce planning to address therapist shortages; certainty around service viability and growth; clear policies and procedures around implementation of IF. This study highlights the need for further discussion and research about how to overcome the barriers to the optimal use of an IF model for those living in rural and remote areas.

**Keywords:** disability, Individual funding, person centred, rural and remote

Individual funding (IF), also referred to as direct payments, involves an annual allocation to an individual with a disability to purchase required support (Disability Policy & Research Working Group 2011, Laragy & Ottmann 2011). Underpinning the increasingly prevalent adoption of IF is the principle of

person-centred practice. Person-centred practice is an individualised approach that recognises a person's unique circumstances, is strengths based, involves the person's family and wider social network and is goal focussed (Mansell & Beadle-Brown 2004, Coulson 2007). Governments worldwide are increasingly

offering individuals with a disability the option of receiving funding through individual allocations based on assessment of need (Lynch & Findlay 2007, Fisher *et al.* 2010, Laragy 2010, Lord & Hutchison 2010, Disability Policy & Research Working Group 2011). Laragy (2010) suggests this shift in funding process is driven by both a human rights stance in keeping with the Convention on the Rights of Persons with Disabilities (CRPD) (United Nations 2006), giving individuals control over the support they receive and an economic rationalist approach to contain service costs.

A shift to a person-centred model and IF *should* allow people with a disability and their carers to leverage greater flexibility and choice in service access. However, individuals who live in rural and remote areas have always had less choice and access to fewer services than their metropolitan counterparts (National Disability Services Victoria 2011). Skinner and Rosenberg (2006, p. 2875) described 'rural limits' that compounded the difficulties of providing health-care services in rural areas. Skinner and Rosenberg attributed these constraints to the geographic, socio-cultural, technological and workforce barriers in rural compared with metropolitan communities.

Occupational- and physiotherapy, speech pathology and psychology (therapy) are important support services required by many individuals with disabilities to maximise community participation. Individuals with a disability and their carers may wish to use IF to purchase therapy. In non-metropolitan areas there is already a recognised shortage of therapists to meet demand (Denham & Shaddock 2004, Keane *et al.* 2011). We found no research exclusively reporting on the use of IF for the delivery of therapy services in either metropolitan or non-metropolitan areas. This study attempts to address a gap in the literature by reporting on the benefits and barriers of using IF to access therapy services from the perspectives of carers of people with a disability and service providers who live and work in rural and remote areas of NSW, Australia.

### The international experience of IF

Most international literature relates to the use of IF to employ personal assistants (Glendinning *et al.* 2000, Stainton & Boyce 2004, Clevnert & Johansson 2007, Grossman *et al.* 2007). These studies identified that people with a disability who use IF to employ personal assistants reported the ability to control the funds has been beneficial to their self-esteem and has given them opportunities to develop supportive relationships and to access new opportunities. Among the

limitations were onerous administrative requirements, a lack of information and eligibility restrictions. The studies by Fortune *et al.* (2005) and Grossman *et al.* (2007) included some people with a disability who lived in rural areas of the USA. For individuals living in areas with low population densities, the authors identified a lack of choice due to few service providers. Cloutier-Fisher and Skinner (2006) and Skinner and Rosenberg (2006) reported on the impact in Ontario, Canada of a restructure of community-based long-term care from a publicly funded system to a 'managed competition' model (Cloutier-Fisher & Skinner 2006, p. 98). Skinner and Rosenberg noted the additional challenges in implementing a market-oriented approach to community care in rural settings due to the limited capacity of the service sector to adapt to increased demand and competition.

### The Australian experience of IF

In Australia, federal and state governments have traditionally provided block programme funding to non-government organisations (NGOs) to deliver specialist services such as accommodation, therapy services, day programmes or employment to people with a disability (Disability Policy & Research Working Group 2011).

One of the earliest and oft-cited examples of the shift in the Australian context from traditional to IF models comes from Western Australia (WA). Since 1988, the WA Disability Services Commission has delivered IF packages to individuals with a disability via a Local Area Coordination (LAC) model (Bartnik & Chalmers 2007). The model was initially developed to meet the unmet needs of people living in rural and remote areas with subsequent expansion to metropolitan areas (Bartnik & Chalmers 2007, Buchanan 2007, Lynch & Findlay 2007). Although the LAC model does not provide IF to purchase therapy services, the separation of service coordination provided by local area coordinators (LACs) from service provision delivered through government, NGO and local community agencies could apply equally to therapy. Two reviews of the WA model conducted 7 years apart reported high levels of service user satisfaction with the LAC model (Disability Services Commission *et al.* 2003, Disability Services Commission 2010). Buchanan (2007) attributes the long-standing success of the WA model to the empowering, collaborative relationship that develops between an individual with a disability and their LAC.

Despite adopting a LAC model based on WA, Spall *et al.* (2005) reported less positive outcomes of the introduction of IF in Queensland. The authors

interviewed 31 people with a disability and 32 carers about their experiences of IF under a 'quasi-market' system. Examples of the services that could be purchased with the IF package included equipment and rehabilitation services, likely indicating therapist involvement. The Queensland study included participants living in one rural and one remote geographic area. The authors concluded that, in large part due to the historically underfunded state disability service sector, the experience of IF did not result in better client outcomes. Participants living in rural and remote areas particularly identified that 'the narrow range of options from which to "choose"' (Spall *et al.* 2005, p. 62) hampered their ability to purchase flexible and responsive service options.

Ottmann *et al.* (2009) reported on the IF experiences, over a 5-year period, of 12 families caring for a person with a disability in metropolitan Victoria. Participants could use their IF packages to purchase 'products and services related to the care of the person with a disability' (p. 469), including therapy. Participants reported benefits from having greater control over finances and an ability to arrange support according to their needs. However, the authors identified that over time some participants felt increasingly isolated due to a paucity of resource information associated with a lack of local, personal support.

### The Australian context for IF

Australian Federal and State Governments have indicated an intention to pursue IF as an option for people with a disability to access the supports they need. In a major reform aimed at universal coverage for all people with significant care and support needs, the Australian Federal Government recently announced the introduction of a National Disability Insurance Scheme (NDIS). It is anticipated that the NDIS will adopt an IF model, although the detail of how this will work and what supports will be covered is still to be determined (Productivity Commission 2011). The NSW State Government, as part of a major policy and funding enhancement programme for people with a disability, indicated that by the end of 2013/2014 anyone receiving disability services in NSW would have the option of using an IF arrangement (Family & Community Services 2011).

Specifically related to access to therapy support, in 2008 the Australian Federal Government introduced IF packages aimed at providing early childhood intervention and support to young children (0–6 years old) diagnosed with Autism Spectrum Disorder (ASD) known as *Helping Children with Autism*

(HCWA) (Families Housing Community Services & Indigenous Affairs 2008). In 2011 this funding was extended in the *Better Start* programme to children (0–6 years old) diagnosed with cerebral palsy, Down syndrome, Fragile X syndrome and moderate-to-severe vision or hearing impairment (Families Housing Community Services & Indigenous Affairs 2011). Access to these programmes requires a formal diagnosis and the IF packages can only be used with service providers or practitioners who are registered on an 'approved provider' panel. Together, the existing and proposed Federal and State IF initiatives mark a significant change in the funding and delivery of disability services in Australia.

### Rural and remote service access challenges

According to the Australian Bureau of Statistics, 37.3% of Australia's population lives outside of cities with populations of 100 000 or more (Australian Bureau of Statistics 2012), and approximately 21% of people living in these areas identify as having a disability (Australian Bureau of Statistics 2009). IF initiatives assume that suitable supports are available and in such quantity and variety that individual needs can and will be met. However, people with a disability and their carers who live in rural and remote areas have less choice and access to fewer supports than their metropolitan counterparts. The discrepancy between metropolitan and rural service access is in part due to a poorly distributed and overworked rural and remote disability and health sector workforce (Dew *et al.* 2012). There has been very little research that has addressed the issues of living in a rural and remote area and using IF to access therapy. Therefore, little is known about how the widespread introduction of IF proposed by Australian State and Federal Governments will impact on therapy access for people living in rural areas. This study reports on a subset of data from a larger study into therapy service delivery for people with a disability living in rural and remote areas of western NSW related to carer and service provider experiences of existing IF packages (Veitch *et al.* 2012).

### Methods

Ethical clearance was received from the Human Research Ethics Committee of The University of Sydney (#10-2009/12194). The study involved a partnership between the government department overseeing services to people with a disability in NSW and researchers at the Faculty of Health Sciences,

University of Sydney. A detailed description of the larger study can be found in Veitch *et al.* (2012).

### Recruitment

Government and non-government organisations assisted with the overall recruitment of 97 service providers and 78 carers of people with a disability living in rural NSW. All participants provided written consent. This study includes data from a subset of participants who reported experience with IF.

### Service provider participant information

Individual funding was discussed in eight focus groups (each including between 2 and 16 participants) involving 21 government and 39 non-government service providers held from March to July 2011. Fifty-three of these participants were female and seven male. Twenty-seven participants were therapists, therapy implementers of programmes written by a therapist or psychologists; 14 were case managers; seven coordinated or managed disability services; six were school or early childhood educators and six were accommodation support workers. Four focus groups were held in large regional centres with populations of 40–60 000 ( $n = 48$  participants); two groups were held in a small rural centre with a population of 20 000 ( $n = 6$ ) and two groups were held in rural areas with populations of <10 000 ( $n = 6$ ) (Australian Institute of Health & Welfare 2004).

### Carer participant information

Eight mothers and two fathers spoke about IF relating to 14 children with a disability. Five carers, including one couple who were interviewed together, had two children with disabilities. From March to August 2011, two of the ten carers were participants in focus groups with other carers (including between two and nine participants) and eight had individual interviews. Ten of the children with disabilities were male and four female and they ranged between 2 and 8 years old (mean age 5 years). All but one of the children had a diagnosis of ASD and received IF specific to that diagnosis. One child had a diagnosis of cerebral palsy. Two carers lived in large rural centres with populations of 40–60 000; one carer lived in a small rural centre with a population of 20 000; three carers lived in rural centres with populations of 1–10 000 and four lived in remote centres with populations of <1000 (Australian Institute of Health & Welfare 2004).

### Data gathering

Separate focus groups or interviews were conducted with service providers and carers. Individual interviews were offered to participants who were not able, or did not wish, to attend a focus group. Focus groups were held in disability organisation offices or in public meeting rooms. Interviews were held in the participant's home, office or in a public space depending on participants' preferences. Focus groups lasted on average 2 hours and individual interviews 1 hour. All focus groups and interviews were organised and conducted by authors AD and KB.

The purpose of the focus groups and interviews was to hear directly from service providers and users about the provision of therapy services to people with a disability living in rural areas. Service provider participants were asked to discuss the impact of policy and workforce on rural therapy service delivery. Carer participants were asked to describe their experiences of using or trying to use rural therapy services for the person with a disability for whom they cared. Within the context of these focus groups and interviews, the data reported in this study relate to participants' experiences with individual therapy funding packages.

### Data analysis

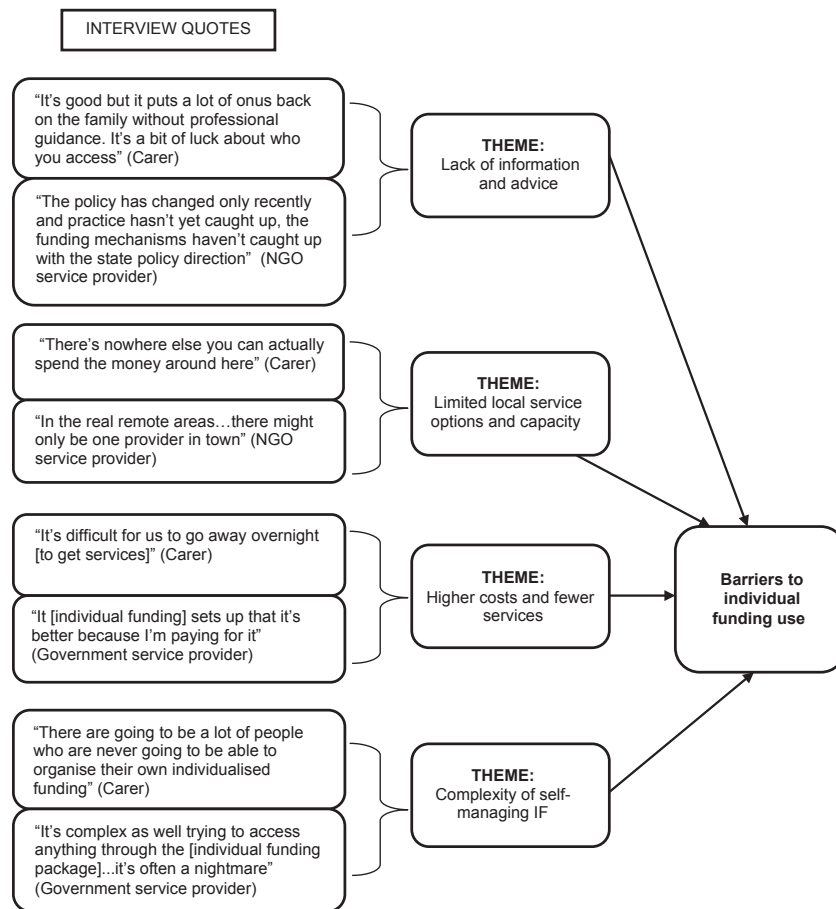
A modified grounded theory approach using thematic analysis and constant comparison were used to analyse the data (Braun & Clarke 2006). The first author conducted the analysis that was then discussed with the other authors. Each transcript was read and emerging issues were noted on a data coversheet. Once each transcript was reviewed in this way, constant comparison was used within and between transcripts to identify similar and divergent issues. Similar issues were then grouped to form emerging themes. The second author conducted an audit on a randomly selected 10% of the total transcripts to verify the identification of themes.

Experiences with using IF packages emerged as a theme within both the service providers and carers' data. Figure 1 provides an overview of how four barriers to the use of individual funding were identified based on analysis of the data.

### Results

Participants acknowledged benefits of receiving IF packages. They also identified four barriers to their use in rural and remote areas: (i) lack of information





**Figure 1** Summary of steps for data analysis identifying barriers.

and advice; (ii) limited local service options and capacity; (iii) higher costs and fewer services and (iv) the complexity of self-managing IF packages. In addition, service providers described some innovative approaches to providing services to people who use IF. Along with a participant number, the letter 'C' is used to indicate Carer participants and 'SP' for Service Provider participants.

### Benefits of IF

The availability of an IF package meant some people had access to therapy that they previously did not have. As one carer said:

We did apply for [IF] under the HCWA package and essentially...for the past year...that's what we've been using to access therapy, that and private money. (C01)

This carer also reported that receiving funding for her daughter in an individual package meant she had more choice in how and where therapy was accessed:

I think the HCWA funding is fantastic because you get access to [therapy] services and it's flexible and it means we've been able to travel to [capital city] and we've been able to get services. (C01)

Another carer reported that receiving an IF package improved her child's access to therapy:

Last year [before getting the IF] we got chopped and changed with [therapy] appointments all the time. There was a lot of gaps. Now the funding has come through we've got much more reliable appointments. (C02)

### Barriers to use of IF in rural and remote areas

Despite appreciating the opportunity to access IF packages for therapy, participants identified a number of barriers to optimal use of IF that related to living in rural and remote areas. The first barrier identified was the lack of information and advice about what therapy services they could use their funding to purchase.

### Lack of information and advice

All carers indicated a need for high-quality, timely and ongoing information to use the IF to full advantage. As one carer explained:

When [my daughter] was first diagnosed, we had the interview...and they did send us quite a comprehensive list of services, some of which seemed prepared to do things for remote areas by [online videoconferencing]...It was a bit overwhelming at the time [and] it probably would have been helpful to have another interview 3 months later. (C01)

This carer further identified that a lack of information can result in poor decisions about how to use the funding:

...but it's also got quite a lot of dangers because we spent our money quite quickly because you're not aware of what you are doing...it's good but it puts a lot of onus back on the family without professional guidance. It's a bit of luck about who you access. (C01)

Non-government service providers also spoke about how a lack of clarity and timely information about the policies related to IF affected service implementation. As one NGO service provider put it:

The policy has changed only recently and practice hasn't yet caught up. The funding mechanisms haven't caught up with the State policy direction. (SP01)

### Limited local service options and capacity

In addition to a lack of information, participants identified limited local service options, especially for those living in smaller rural communities. As one carer described:

There's nowhere else you can actually spend the money around here...it won't be a very long list [of approved providers], not out here..... you might get offered an extra [session] and you might get a bit more say in what you choose. (C03)

Another carer said:

I can't pick and choose [the service provider]...there's the service here or there's one in [another town]. (C04)

Service providers also identified problems with implementing IF in rural areas due to the limited pool of providers. One NGO service provider said:

...the trend towards client directed funding [is] a great model [and] I think everyone supports it in principle, providers and consumers alike. In the metropolitan areas [there are] many, many different agencies to refer to, great choice for the consumer...[but] in the real remote areas...there might only be one provider in town or a generic provider

100 km away in the bigger town, so client directed [funding], it can't happen because there's no choice for the consumers anyway. (SP02)

A staff member from an early intervention service that operates in a geographically isolated town said:

We've been trying to encourage more families to use [IF] but they feel 'why go through all that [bureaucracy] if we can't use the money [due to lack of local services]?' (SP11)

Another NGO service provider said:

I'm really honest with families, especially when I go to [small rural town]. I'm like 'if this [therapy option] isn't going to work, we need to be honest because it's a lot of money out of your package' and that makes it difficult because in regional areas, families are kind of, 'I've got nothing else to spend my money on'. (SP04)

In addition, carers reported concerns about local service capacity to extend services to those with IF while at the same time providing for 'block-funded' clients as explained by this carer:

Now that service is going to have more people with that funding [so] who's going to be pushed out? They can only give what they can give. (C05)

Indeed, this view was confirmed by a number of NGO service providers who deliver early childhood intervention therapy:

Our therapists are already stretched to be employed as much as they can [be]. (SP05)

We were flying therapists to [this rural town] and [that rural town] and trying to do clinics to meet the [IF package] needs but it wasn't financially viable. (SP07)

We've only got a physiotherapist who is working 3 days [per week] so we've got no potential to be able to increase the physio services under [IF schemes]. (SP06)

People with complex needs living in more remote areas may require access to specialist therapy beyond the expertise of the generalist therapist working in their town. As one carer explained:

Because there are only a limited number of children in [my town] with [this disability], the therapists locally can only work within the experience they have [so] it's just a different situation. (C06)

Another aspect of the issue of limited local service options is the fear of NGOs that IF will create uncertainty in workforce planning as described by this service provider:

Services aren't putting on the occupational therapists and speech [pathologists] because there's not that guarantee that you're going to have the wages. (SP07)

Service provider participants feared that this uncertainty may lead to service viability issues, particularly for smaller organisations, which abound in rural and remote locations.

Having access to limited local service options can create problems for carers trying to use their allocated IF within a specified time period. One carer reported:

The transition person rang us and said 'Look we've got to do something. Your money will be gone; it won't be long at all and you haven't managed to spend a cent of it'. (C07)

### Higher costs and fewer services

For carers who lived in rural and remote areas, the need to travel to access services was significant and involved not only the financial costs of airfares, petrol, accommodation and food but also personal costs including time off work, childcare for other children and distance from emotional supports. A carer explained:

It's difficult for us to go away overnight [to get services]. The little guys don't go very well when we stay somewhere else. (C07)

Some IF packages provided additional money to cover travel for those who lived in rural and remote areas. However, a number of carers indicated that these additional funds did not cover the actual costs of accessing city-based services as reflected in this quote from a carer:

We could go to [service in capital city] for a week but you can't afford to. You've got other kids [and need to] stay in a motel. (C08)

Instead of travelling, some carers decided to use their IF package to bring a city-based therapist to their town. This approach had different cost implications as reflected in this comment from a carer, who has two children with a disability:

[A therapist] wanted to fly down from [capital city], do an assessment on the two boys which I would have had to pay for out of my [IF] – airfare, two consultations (\$365 each), her motel accommodation for the night. So that would have been about \$800 per child. (C09)

Similarly, a government service provider said:

It's complex as well, trying to access anything through the [IF package]...It's often a nightmare and it has cost several of my families...who live out in the middle of nowhere... about \$2500 [of their \$6000 package] to get a [private] speech pathologist and [then] they don't work with any of

the other agencies that the child is involved with.... [Carers] didn't get value for money. (SP09)

Carers also spoke about the restrictions, placed by the Federal IF schemes, of having to use therapists who were listed on an approved provider list:

The money never physically came to us to go and do anything....We had an allocation to use but we had to use it [with prescribed providers].... The system should be more flexible. Having your choice of service provider was good but once you locked into a service provider, then they had to get everything for you.... And, of course, everything had a mark up on it to cover their administrative costs. So it wasn't IF as such. It was block funding given to a service provider on your behalf. (C09)

### Complexity of self-managing IF packages

Carers expressed the view that not all families would be able, or wish, to manage an IF package. One carer said:

There are going to be a lot of people who are never going to be able to organise their own IF....Those people will hopefully have a relationship with a service provider who they trust that will be able to do that for them. (C09)

Similarly, another carer expressed her belief that:

[IF] works very well for middle class families or people with education and the ability to find out those things but I don't know that it does for all [families]. (C01)

Some programmes imposed strict timeframes regarding diagnosis and processing of the IF application. A carer reported on the difficulty she experienced meeting the deadline:

I didn't fill out the form in time.... That was my fault. I didn't have the strength to sit down and process that. I just was taking it each day at a time [but] because he wasn't diagnosed, he didn't [get]... funding. (C010)

Another carer spoke about the difficulty of spending the money within the allocated period:

We got the money in February but we had to use it by the end of October. (C03)

A NGO service provider concurred with this view:

Families feel under pressure to use the funds.... It's [IF package] not family-centred. (SP01)

The complexity of the IF system was also highlighted by another NGO service provider:

There's no guidelines [for additional funding for travel expenses]...you can argue with your [IF package advisor] that you need to travel, that the service that you require

wasn't within your region.... [But] they won't tell you that unless you ask for it. (SP10)

### Innovative approaches to providing IF services

Participants identified a number of innovative approaches to providing services to people with a disability who had IF packages and lived in rural and remote areas. One approach was for carers to pool their IF packages to employ a 'fly-in, fly-out' therapist to travel regularly to their town to provide individual and group interventions. Similarly, participants gave examples of schools and health-care settings that formed partnerships with private practitioners to provide therapy utilising clients' IF packages. The private therapist linked in with local therapists employed in government or NGO agencies, using a fee-for-service model. Another approach in more remote communities was the employment of local people trained to work as therapy implementers under the direction of therapists based in regional towns. The key to the success of these innovative strategies was that they enhanced local workforce development and community engagement. Hence, capacity was built within the local community to the benefit of people with and without a disability living in the area.

### Discussion

The global movement towards self-determination, choice and community inclusion of people with a disability encapsulated in the CRPD (United Nations 2006) is likely to result in IF models increasingly becoming governments' preference for delivering funding. All people with a disability, regardless of whether they live in metropolitan or non-metropolitan areas, should be able to make decisions about how best to spend an IF allocation to meet their need for support. It is not clear at this stage to what extent the introduction of the NDIS in Australia will result in an open market approach including an expansion in 'for-profit' providers as described in Ontario, Canada by Skinner and Rosenberg (2006). Australia would do well to heed Skinner and Rosenberg's warnings about the rural limits of a market-oriented model given that there are already fewer therapists working in rural areas than can meet the demands for support. Spall *et al.* (2005), Fortune *et al.* (2005), Skinner and Rosenberg (2006), Grossman *et al.* (2007) and participants in this study, identified limited service availability and increased costs for those living in smaller and more remote geographic locations. There is a need, therefore, to develop alternative

approaches to assist rural-based people with a disability and their carers to make use of IF.

### Information and support to navigate a complex system

Participants in this study identified a lack of information about what is available and support to navigate a complex system as two barriers to the effective use of IF. A lack of information and support related to decision-making and optimal use of IF options were also mentioned as problematic by Ottmann *et al.* (2009) and Grossman *et al.* (2007). In contrast, the system of LAC described by Bartnik and Chalmers (2007) and Buchanan (2007) highlighted the ongoing relationship with a person who assisted the person with a disability and their carers to access information was a crucial factor in the success of the IF approach in WA.

One-off, centrally based information 'hot-lines' described by participants in this study were reported as inadequate for providing useful information to help people make complex decisions about where and how to spend their allocated funding. Service providers in this study also identified the need for clear yet flexible guidelines around IF models so they too have accurate information. This study and the research by Ottmann *et al.* (2009), Grossman *et al.* (2007), Bartnik and Chalmers (2007) and Buchanan (2007) highlight the need for ongoing access to high-quality, local information and support for both service users and providers. As recommended by Mansell and Beadle-Brown (2004), information and support are necessary for person-centred approaches that aim to empower individuals to make informed decisions including about the effective use of IF. The need for high-quality information and support are not particular to rural-based people, although both are likely to be 'thinner on the ground' in geographically isolated areas.

### Limited service options and higher costs

Two important factors are particular to rural and remote areas: limited local service options and higher costs associated with accessing available services. Reflective of the findings of Spall *et al.* (2005), Fortune *et al.* (2005) and Grossman *et al.* (2007), carer participants in this study identified the small pool of locally based service providers with whom to use their IF as resulting in a lack of choice that meant they either could not spend their IF or spent it on things that may not be their highest priorities. Alongside limited choice was service providers' limited capacity to extend their services to meet increased demand. The difficulty of recruiting and retaining staff to work in



rural and remote locations results in service providers not being able to expand their service options even if they are both willing and have the financial capacity to do so (National Disability Services Victoria 2011, Dew *et al.* 2012). According to participants in this study, a lack of choice and limited capacity were associated with less access to therapy. Participants also reported increased costs due to the need to travel long distances to access services. Service providers were fearful of the impact of IF on workforce planning due to uncertainties about the demand for their existing service model by service users with discretionary funds.

### The way forward for individual therapy funding in rural and remote areas

The viewpoints of service users and providers highlight particular considerations that will need to be addressed in rural and remote areas in order for IF to meet the therapy needs of people with a disability and their carers. Based on our research and the literature, we suggest that to optimise their use of IF therapy packages, service users who live in rural and remote areas need:

- (1) Access to timely and up-to-date information available in a variety of formats, including by telephone, online and in hard copy.
- (2) Personal contact with someone, such as a LAC, with whom they can build rapport, get answers to questions and discuss support options. Contact may be face-to-face, by telephone or via the internet.
- (3) Adequate financial compensation to cover the additional costs incurred in travelling to access supports. Streamlined and coordinated eligibility and accountability systems that encourage and assist people to use IF options.
- (4) Flexible innovative support options that build capacity in local communities to the benefit of all those who live there (e.g. by developing inclusive networks, strategies and skills among local community members and organisations).

Service providers who support people with IF therapy packages in rural and remote areas need:

- (1) Engagement with policy-makers in the development of a coordinated approach to IF therapy models.
- (2) Collaborative local workforce planning, recruitment and retention strategies aimed at addressing therapy workforce shortages.
- (3) Certainty around service viability and growth.
- (4) Clear policies and procedures around using IF packages for direct therapy implementation as well as to support others to implement therapy programmes.

The findings reported here have limitations for broader applicability as the IF participants discussed was only available to children in the 0- to 6-year age bracket with specific diagnoses including Autism Spectrum Disorder and cerebral palsy. IF was not the focus of the larger study from which these data were extracted, but was raised by participants as part of the broader discussion of provision of therapy services.

### Conclusion

The commitment to IF approaches by governments worldwide will mean that increasing numbers of people with a disability who live in rural and remote areas will receive IF to pay for the supports they require including therapy. This study highlights the need for further discussion and research about how to overcome the barriers to the optimal use of an IF model for those living in rural and remote areas.

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### Conflict of Interest

Authors Kim Bulkeley and Scott Griffiths are employees of the Department of Family and Community Services, Ageing, Disability and Home Care, NSW.

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