

What is a person-centred approach? Familiarity and understanding of individualised funding amongst carers in New South Wales

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Abstract

Person-centred approaches place individuals with a disability at the centre of decision making, with their carers and family invited to be partners in the process. Rather than being required to fit within existing service programs, person-centred approaches enable individuals to choose the support options that best meet their needs. In order to facilitate this, person-centred approaches will be accompanied by the introduction of individualised funding. This means the individual will be provided with funding to purchase services of their choosing. Given these significant changes occurring in the disability sector, Carers NSW surveyed informal carers of people with a disability to identify what they knew about person-centred approaches and how they felt about their introduction. Survey results indicate that there is a need to increase the capacity and willingness of carers significantly in order to engage with person-centred approaches and individualised funding. Carers require targeted and comprehensive information about these concepts in order to understand fully the changes occurring within the disability sector. These findings also indicate specific areas that need to be addressed in order to increase carers' awareness of these concepts and also to address existing negativity and confusion.

Keywords: carers; informal care; person-centred approach; disability; individualised funding

Introduction

Person-centred approaches (PCAs) encourage acknowledgement of – and advocacy for – the human rights of people with a disability as set out by the United Nations Convention on the Rights of Persons with a Disability (UN 2006). Governmental bodies that have ratified the Convention recognise that people with a disability are individuals and should be entitled to choice and control over the services they receive. The disability field has therefore been experiencing a paradigm shift away from expert professional control towards individual choice, personal empowerment and community participation (Pedlar et al. 1999; Nelson et al. 2001; Lord & Hutchison 2003). Person-centred service systems aim to enable individuals, carers and families to arrange services to suit their own lives – the importance of which has been widely recognised (Lord & Hutchison 2003; Tisdall 2006; Arksey & Kemp 2008; Ottmann et al. 2009). Such approaches have been implemented internationally, most notably in the United Kingdom (UK), but also within Australia, including in the NSW disability sector.

The overarching feature of PCAs is a respectful, collaborative partnership between people with a disability and service providers, in which the place of the individual within the family and the community is valued (Sanderson 2000; NARI 2006). Including family and friends is central to the success of PCAs (Maudslay 2002). However, successful inclusion relies on providing carers, family members and friends with relevant information about service options (Dowling et al. 2006).

This paper specifically focuses on the perspectives of carers of people with a disability towards PCAs and individualised funding, where a carer is defined as any individual who provides unpaid care and support to a family member or friend who has a disability. This focus is due to the introduction of PCAs in the NSW disability sector.

The little empirical evidence that exists within the literature is largely supportive of PCAs (NARI 2006; Glendinning et al. 2009; Ottmann et al. 2009; Moran et al. 2012; Netten et al. 2012). Many people with a disability have reported positive outcomes from having greater control and choice over resources (Glendinning et al. 2008). However, as PCAs have only recently been formalised within policy directives, thorough empirical research regarding their effectiveness remains limited. In the same way, carers' current attitudes towards these changes are likely to be relatively uninformed.

PCAs in New South Wales

In keeping with national disability reforms, the NSW Government plans to provide people with a disability, their families and carers with increased control and choice in terms of the support services they receive (ADHC 2012). This approach to funding and service provision intends to address concerns raised by the Productivity Commission Inquiry (Productivity Commission 2011), which identified Australian disability services as fragmented, insufficient, and

inequitable. Through the introduction of PCAs, the NSW disability service system will aim to address these concerns by allowing individuals, families and carers to exercise control over the services they receive, and to support individuals' participation in the community (ADHC 2012). An important aspect of this is the choice individuals have in terms of their personal control regarding organising services. That is, they will have the opportunity to manage funding packages personally, or choose to negotiate for this responsibility to be taken on by an external party (ADHC 2012). Infrastructure supports, including brokers or facilitators, have been found to be particularly useful resources in enabling people with disabilities and their carers to negotiate person-centred systems and initiate service provision (Lord & Hutchison 2003). Providing options regarding the degree of personal control over funding packages emphasises the person-centred nature of this policy approach. This is particularly significant in attempting to meet the needs of as many people with a disability – and their carers – as possible, and in adhering to the underlying assumption of PCAs that one size does not fit all.

These reforms to the NSW disability sector must be viewed in the broader national context. National schemes such as Helping Children with Autism and Better Start have already implemented PCAs in early intervention contexts. The national implementation of PCAs will continue to expand, particularly through the current trial sites and impending rollout of the National Disability Insurance Scheme (NDIS). The NDIS is intended to reform disability services across Australia, such that PCAs will become the standard approach throughout the sector. This imminent comprehensive change to disability services emphasises the importance of understanding PCAs and individuals' responses to them. Although little is currently known about the place of carers within the NDIS, the focus of PCAs on the individual with a disability is likely to hold certain implications for carers' personal attitudes towards such approaches.

Individualised funding

A fundamental mechanism in establishing a person-centred system is individualised funding (IF) (O'Brien 2001; Lord & Hutchison 2003). Under these arrangements, funding is not directly allocated to services, but rather to individuals, who can then dictate which services they receive and from whom (Lord & Hutchison 2003; ADHC 2012). Similar approaches have been introduced in the UK with seemingly positive results. The Individual Budgets Evaluation Network found that these funding arrangements had the potential to increase the sense of control and satisfaction experienced by service users and their carers (Glendinning et al. 2008; Glendinning et al. 2009). However, the evaluation also found that, compared to previous systems, older people experienced lower psychological wellbeing under an individual budget system, and were also more guarded about individual budgets than their younger counterparts. Other research suggests that older cohorts required the most assistance in navigating their funding arrangements, due to being less-informed than younger cohorts (Bartlett 2009; Moran et al. 2013). Confusion and

misunderstanding surrounding the use of personal budgets has been found to result in service users feeling less confident about their choices and control (MIND 2009), which is clearly the opposite of what such a system intends. Providing support around understanding system changes and clarifying any issues of concern therefore appear to be crucial strategies in ensuring that the ultimate aims of PCAs are met, particularly amongst older carers.

Importantly, within a truly person-centred system, individuals will have choice over how their funding is managed, whether by individuals and families themselves, or by an external party (ADHC 2012). These arrangements, and combinations thereof, have been trialled in the UK, with evidence again supporting their beneficial outcomes (Glendinning et al. 2009; Moran et al. 2012). However, the uptake of direct payments has been relatively low among carers in the UK (Fletcher 2006). In light of this, the revised English National Strategy for carers focuses on the benefits of personal and individual budgets for carers (Glendinning et al. 2009). Emphasising the ways in which managing an IF package can be personally beneficial is thus seen as a central way in which to encourage engagement, and thereby realise the full range of choice and control that such a system intends. The importance of emphasising potential positive outcomes can be seen when benefits and burdens are simultaneously considered. For example, one small-scale English study suggested that additional responsibilities counteracted the benefits of increased choice and control (Williams et al. 2003). However, larger evaluations of the impact of individual budgets have found that carers of individual budget users reported significantly higher quality of life and psychological wellbeing than the control group, while not incurring any greater public cost (Glendinning et al. 2009). While these findings suggest that managing IF packages may not necessarily result in a net improvement in every individual circumstance, they do indicate that strong personal benefits are possible. Furthermore, PCAs allow individuals to determine for themselves how much responsibility they undertake in managing funding packages, which provides the opportunity for each individual to determine which approach will best meet their needs.

The proposition of enhanced choice and control purported by PCAs and IF is predicated on an assumption that sufficient services will be available to allow people with disabilities and their carers to have meaningful choice. This issue is of particular concern to carers and people with disabilities living in rural regions. Previous research has demonstrated that significant difficulties exist in accessing services amongst rural carers compared to their urban counterparts, due to service availability, travel implications, and associated financial costs (for example, Dew et al. 2013a; Edwards et al. 2009). Furthermore, recent research investigating the experiences of rural carers in NSW has identified particular barriers faced in using IF packages, including lack of information, limited service options, waiting times, travel, costs and complexity in managing services (Dew et al. 2013b). Therefore, access to legitimate choice in rural and remote areas is a specific concern worthy of consideration in the implementation of a person-centred system. While service availability is an issue of particular concern

in rural areas, it is also worth noting that it may well apply to varying degrees across other geographical regions – for example, inequalities may also exist between different metropolitan areas.

Carers and PCAs

A majority of the literature on PCAs focuses on governmental or service provider perspectives, with little pertaining to carers' perspectives (NARI 2006). However, carers play a vital role in supporting people with a disability, and therefore ought to receive due consideration within a person-centred system (Ericson et al. 2001; ADHC 2012). While people with a disability are entitled to participate actively in making decisions about their own lives, these decisions are often made in collaboration with carers and other family members or friends whose inclusion in disability service providers' mandate has been suggested (Guberman et al. 2003; Mitchell 2012). An issue also exists surrounding the simultaneous needs of people with a disability and their carers, and the degree to which PCAs or IF can accommodate these needs, particularly when misalignments occur (Glendinning et al. 2009). Considering the central role of carers in supporting people with a disability, and the potentially different needs that may exist between people with a disability, carers and service providers, carers' attitudes towards PCAs are worthy of due respect. This is particularly the case in situations where carers act as primary or influential decision makers regarding the services used by a person with a disability. This study therefore has sought to investigate carers' familiarity and understanding of PCAs and IF, including their personal expectations, hopes and concerns.

Method

Carers NSW biennial survey

Carers NSW conducts biennial surveys in order to collect information about carers in NSW and inform the organisation's advocacy work. The 2012 survey contained one particular section focusing on the introduction of PCAs.

The survey was made available online and as a paper questionnaire to carers across NSW. Paper questionnaires were distributed to Carers NSW members and an online link to the survey was promoted on the Carers NSW website. A number of other stakeholders also promoted the survey via their websites and distributed copies through their networks. Only carers over the age of 18 were invited to complete the survey.

Participants

Completed surveys were received from 1,916 carers, with 45.8 per cent (n=878) indicating that the person they care for used services from the disability sector. A demographic breakdown of the full sample and those from the disability sector is provided in Table 1.

Table 1: Participant demographics

		All (N=1916)	Disability (N=878)
Gender	Female	82.5%	85.6%
	Male	16.2%	14.2%
Age (years)		18-100 (M=55.74)	18-89 (M=53.12)
ATSI		2.8%	3.0%
CALD		16.1%	13.3%
Education	Bachelor	28.3%	29.0%
	Diploma	16.5%	14.8%
	Year 12	10.3%	11.5%
	Year 10	20.7%	20.8%
Region ¹	Urban	50.1%	47.9%
	Regional	36.1%	39.6%
	Remote	10.9%	10.7%
Employment	Paid work	39.7%	40.8%
	Studying	8.7%	10.5%
	Not working	43.6%	43.1%
Carers NSW Member		52.6%	54.9%

Note: ¹Participants were asked to self-select whether they lived in an urban/metropolitan, regional, or rural/remote area.

The demographic breakdown of respondents in contact with the disability sector is very similar to that of the full sample of survey respondents. Female carers were overrepresented (82.5 per cent), compared to recent Australian Bureau of Statistics (ABS) data that estimate 56 per cent of carers are female (ABS 2012). However, it is worth noting that 70 per cent of primary carers are female (ABS 2012), and primary carers comprised 92 per cent of the present sample. The mean age of survey respondents (55.74 years) reflects ABS data, where the highest proportion of carers were aged between 45 and 64 years (ABS 2012). The present sample had completed higher levels of education than the wider carer population, with 28.3 per cent having completed bachelor or higher degrees, as opposed to 17.8 per cent estimated by the ABS (2012). Approximately 40 per cent were in paid employment – fewer than the 52.5 per cent estimated by the ABS (2012). Half of the total sample lived in urban areas and slightly over half were members of Carers NSW.

Survey questions

Participants were asked whether or not they had heard of PCAs and IF, and if so, whether or not they understood what each entailed. Following these questions, a brief description of both concepts was provided to assist participants in responding to subsequent questions. They were asked whether or

not they would manage IF themselves if given the option, as well as the barriers that would prevent them from doing so, and what assistance they felt they would need.

Finally, respondents were asked how they expected the introduction of PCAs and IF to affect seven specific outcomes on a scale of one (a lot worse) to five (a lot better):

1. The control carers have over services
2. The control the people they care for have over services
3. The choices carers have in how they live their lives
4. The choices the people they care for have over how they live their lives
5. The degree to which carers' needs are met
6. The degree to which the needs of the people they care for are met
7. Finding and organising services

Results

Familiarity with PCAs and IF

As expected, a larger proportion of carers involved in the disability sector had heard of both PCAs (39.5 per cent) and IF (51.9 per cent), compared to those from other service sectors (24.8 per cent and 25.9 per cent respectively). These differences between sectors were statistically significant, $\chi^2(1)=36.667$, $p=.000$ (PCAs), and $\chi^2(1)=118.509$, $p=.000$ (IF). Interestingly, a larger proportion of participants had heard of IF than the more general concept of PCAs.

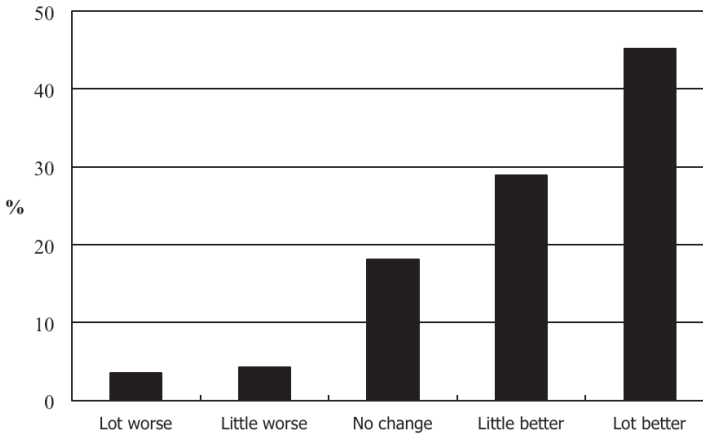
Although carers within the disability sector were more likely to have heard of both concepts, these figures demonstrate a relatively low level of awareness across all sectors. However, of those carers who indicated that they had heard of these concepts, a very high percentage believed that they understood what each entailed, with 90.5 per cent of disability carers understanding PCAs – compared with 87.3 per cent of other carers – and 84.9 per cent of disability carers understanding IF – compared with 82.2 per cent of other carers. This shows that the vast majority of carers who had heard of PCAs and IF also believed that they had an understanding of them, regardless of which service sector/s they were in contact with.

Since PCAs are initially being introduced into the disability sector, the views of carers within this sector were of particular interest. Therefore, the remainder of findings focus solely on the survey responses of carers who have contact with disability services.

Expectations of the impact of PCAs

Overall, expectations of the impact of both PCAs and IF were very positive, with 74 per cent of responses indicating the expectation that PCAs and IF would make things either a little or a lot better (see Figure 1).

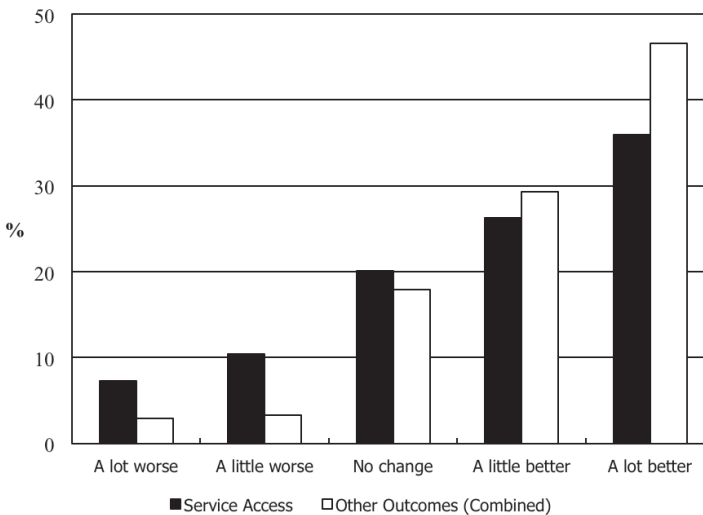
Figure 1: Expectations of the overall impact of Person-centred Approaches (PCAs) and IF



Despite previous literature having identified a range of barriers to the use of IF in rural areas, the distribution of responses regarding these expectations was not significantly different between geographical regions, $\chi^2(4)=2.158$, $p=.707$.

Expectations regarding the first six outcomes showed very similar distributions. However, expectations of how PCAs and IF would affect finding and organising services was significantly less positive, $\chi^2(4)=203.942$, $p=.000$, as demonstrated by Figure 2.

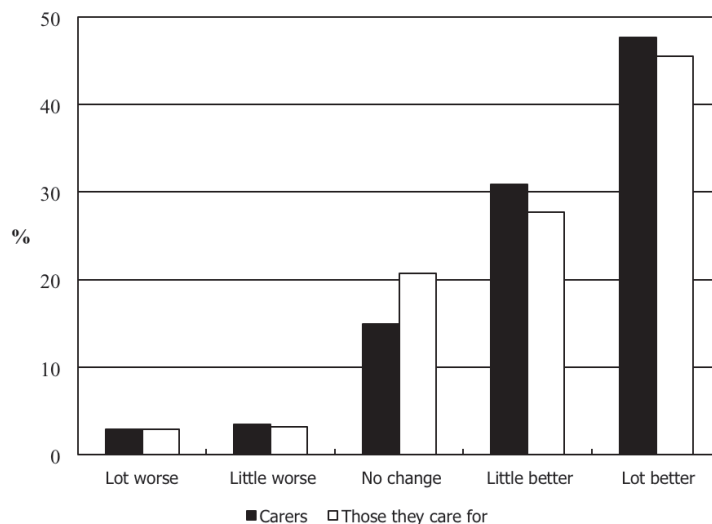
Figure 2: Comparative expectations of access to services and other outcomes (combined) under PCAs and IF



A majority of survey respondents (62.2 per cent) still believed that service access outcomes would improve. However, the proportion of respondents who expected that finding and organising services would be negatively impacted was significantly larger than those who thought other outcomes would be negatively affected. Similarly, the proportion of respondents who expected that finding and organising services would be better under a PCA was significantly smaller than those who expected positive effects for other outcomes. Once again, despite literature suggesting difficulties in accessing services in non-metropolitan areas, the distribution of responses was not significantly different between geographical regions, $\chi^2(4)=3.752$, $p=.441$.

Participants were asked to respond regarding their expectations for three specific outcomes directly related to themselves as carers and those they care for – that is, control over services, choices in how to live their life, and the degree to which needs are met. Again, responses were predominantly positive, with 78.6 per cent of outcomes for carers and 73.2 per cent of outcomes for those they care for expected to demonstrate some level of improvement. As shown by Figure 3, expectations were more positive for carer-related outcomes than for those related to the people they support, $\chi^2(4)=44.053$, $p=.000$.

Figure 3: Expectations of how PCAs and IF will affect carers and those they care for



A larger proportion of respondents indicated that they believed the introduction of PCAs and IF would result in better outcomes for themselves than for those they support. Alongside this, the proportion of respondents who believed that there would be no change in outcomes for the people they care for was larger than the proportion who believed there would be no change for carers themselves. Importantly, only a very small percentage of respondents expected that the introduction of these approaches would result in worse outcomes for either themselves or those they support – approximately six per cent each.

Stepwise linear regression analysis was conducted to determine factors that significantly predicted overall ratings of the expected effects of managing IF. Independent variables considered in this analysis included demographic variables – gender, age, education, employment – and participants’ familiarity and understanding of both PCAs and IF. The dependent variable was participants’ combined ratings of how they expected managing IF to affect them and the people they cared for, applied across the seven outcomes previously outlined. Residual statistics were examined in order to remove any statistical outliers from the analysis. The final regression model is shown in Table 2.

Table 2: Regression model to predict expectation of managing Individualised Funding (IF)

Variable	Coefficient
Constant	32.968 [1.127]
Age	-.091** [.018]
Education	.342* [.146]
N	502
R2	.064

Notes: Standard errors in parentheses. Education was measured according to the following categories: less than year 10; year 10; year 12; TAFE certificate or equivalent; Diploma or equivalent; Bachelor degree or higher.

*p < .05

**p < .01

This regression model demonstrates that more positive expectations of managing IF were predicted by younger carer age and higher levels of formal education. However, this model accounted for just 6.4 per cent of the variance in reports of expectations regarding the management of IF.

Managing own IF

Over half – 57.1 per cent – of carers from the disability sector indicated that they would take the option of managing their own IF should it be made available. Respondents who previously knew what IF was were more likely to want to manage the funding themselves than were those who were unfamiliar with the concept (see Figure 4).

As can be seen in Figure 4, those who were familiar with IF were significantly more likely to choose to manage funding themselves, displaying less uncertainty about this choice, $\chi^2(2)=18.187$, $p=.000$. Interestingly, the proportion of respondents who were not interested was very similar.

Reasons for not wanting to manage IF

Respondents who indicated that they would not like to manage their own IF, or were not sure, were asked why this was the case. The three most common responses were:

1. it sounds too complicated,
2. not feeling that they had the time, and
3. not feeling they had the necessary skills.

Figure 4: Likelihood of managing own IF if available

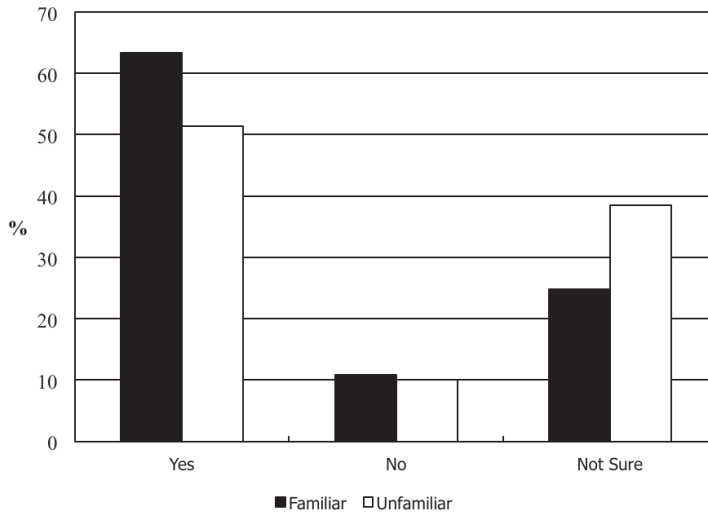


Figure 5: Most common reasons for not wanting to manage IF

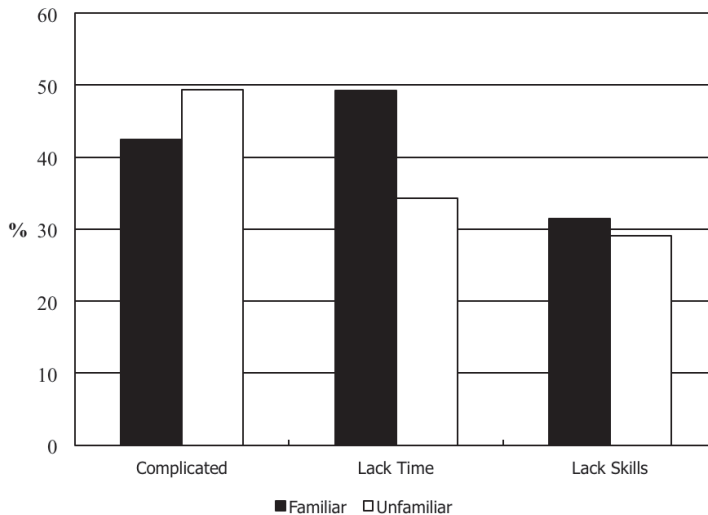


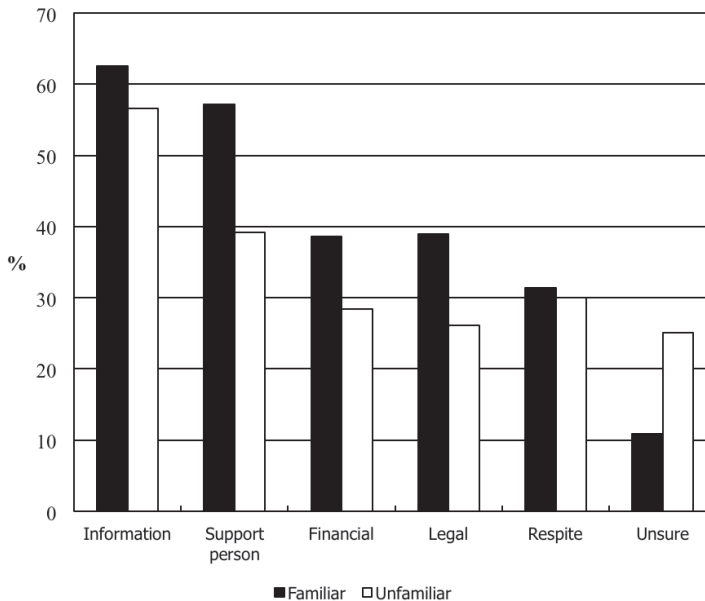
Figure 5 compares carers who were familiar with IF with those who were not in terms of their reasons for not wanting to manage their own funding package.

The perception that managing IF would be too complicated was the most commonly cited reason for not wanting to take on this responsibility. Figure 5 shows that carers were less likely to respond as such when they were familiar with the concept of IF, though this was not statistically significant: $\chi^2(1)=1.196$, $p=.274$. At the same time, those respondents who were familiar with IF were significantly more likely to believe that they would not have the time to manage it themselves: $\chi^2(1)=5.689$, $p=.017$. Among those familiar with IF, the most commonly cited reason was a lack of time, suggesting differences in perceptions between the two groups. Those familiar with IF were also slightly more likely to believe that they would not possess the necessary skills to manage a funding package, although this was not statistically significant: $\chi^2(1)=.151$, $p=.698$.

Carers' needs in managing IF

Participants were asked what forms of training or support they believed they would need if they were to manage IF. The most commonly identified needs were information sessions, a support person/organisation, financial advice, legal advice, and additional respite to allow more time. A comparison of responses between carers who were either familiar or unfamiliar with IF is presented in Figure 6.

Figure 6: Most commonly identified needs in managing own IF



Understandably, those respondents who were unfamiliar with IF were significantly more likely to be unsure as to what support they would require: $\chi^2(1)=28.758$, $p=.000$. On the other hand, those who were familiar with IF were significantly more likely to indicate that they would need a support person:

$\chi^2(1)=27.385$, $p=.000$; financial support; $\chi^2(1)=9.896$, $p=.002$; and legal support: $\chi^2(1)=15.791$, $p=.000$. There was no significant difference between groups in terms of their perceived needs for information: $\chi^2(1)=3.124$, $p=.077$, or additional respite: $\chi^2(1)=.181$, $p=.671$, despite these needs both being regularly identified by participants across both groups.

Predicting the desire to self-manage IF

Stepwise linear regression analysis was conducted to determine what predicted carers' desire to manage IF themselves. Only those responses from participants who indicated that they knew what IF was were included in this analysis. Independent variables considered for this analysis included expectations as to how managing IF would affect the control, choices, and needs of both carers and those they care for, and access to services. The dependent variable was the reported likelihood of taking the option of managing IF themselves. Residual statistics were inspected to determine any statistical outliers, which were then excluded from the analysis. The final regression model is presented in Table 3.

Table 3: Regression model to predict desire to manage IF

Variable	Coefficient
Constant	.099 [.284]
Expectation of how managing IF will affect the degree to which the needs of the person you care for are met	.360* [.065]
N	341
R2	.309

Note: Standard errors in parentheses. Expectation of managing IF rated on scale of: a lot worse, a little worse, no change, a little better, a lot better.
* $p < .01$

The only variable that was found to be significantly associated with an increased desire to manage IF packages was a positive expectation of how the needs of the person they care for would be met. This regression model accounted for 30.9 per cent of the variance in responses regarding the desire to manage IF.

Carers' feelings towards PCAs and IF

The final question in this section of the survey was a free-response question, asking carers about their overall feeling towards the introduction of PCAs and IF. A total of 548 disability carers responded to this question, with responses coded into the following categories:

1. Positive (37.0 per cent of responses)
2. Tentative (19.2 per cent)
3. Unsure/Neutral (16.6 per cent)
4. Sceptical (18.1 per cent)
5. Negative (9.1 per cent)

As with the quantitative results, responses to this question were more positive than negative. However, qualitative data revealed varying degrees of uncertainty that were not as apparent with the quantitative results.

Positive

Positive comments demonstrated carers' optimism regarding the possibilities they envisaged under a person-centred system and the desperation felt by some in terms of the need for such an approach to be implemented:

I am so relieved and optimistic by the very possibility!
(Female, age 62).

PLEASE implement this. I can choose the right path for the people I care for. WE NEED THIS
(Female, age 40).

Some carers expressed their positive views through hopes for improvements in the quality of available services, as those with poor standards would be unable to maintain a client base.

I think this is an excellent idea as it could lead services, particularly public services, to improve their service standards or struggle to attract consumers/clients
(Male, age 55).

A desire for independence was evident throughout the positive comments. Carers suggested that the personal control they envisaged would enable people with disabilities to live their lives how they wanted, which would significantly increase their quality of life.

I believe that individualised funding and person-centred support are essential to enable individuals to live their lives the way they want ... a good life
(Female, age 60).

I think more control over your funding you can live to the full with your disabilities and that makes as good as it gets (sic)
(Male, age 60).

Reflective of the regression analysis results described earlier, perceived outcomes for the person with a disability were described as significant reasons for holding positive hopes for the introduction of PCAs.

Tentative

Tentative comments indicated positive hopes, but also an awareness of certain conditions that would be necessary to ensure the success of PCAs and IF. The general sense was that the proposed changes would work well with some provisos.

Would work well if I was given necessary information to support my choices
(Female, age 47).

Feel it is a positive thing if funded correctly
(Female, age 53).

These carers also demonstrated an awareness of limitations within the service system that could potentially impede the effectiveness of PCAs and IF.

While the overall concept sounds great, I am aware of the limited services out there and the costs involved for private services
(Female, age 46).

Although holding optimistic views, carers who made tentative comments remained grounded in terms of understanding the assistance and direction they would personally require to make the new system work effectively for them.

It appears to offer a responsive approach in giving carers and cared greater control and say over resources – however, its success is dependent on that choice being an informed or educated choice
(Female, age 59).

These tentative quotes therefore offer insight into some of the concerns carers have regarding the implementation of PCAs and IF.

Sceptical

Sceptical comments acknowledged the potential for positive impacts of PCAs and IF, but emphasised serious doubts regarding the practicality of their implementation. The message underlying these responses can be summed up by the following comment:

Sounds good, probably isn't
(Female, age 63).

Those carers who elaborated on specific reasons why they thought there would be problems with this seemingly positive approach raised issues such as increases in their own burden and the adequacy of resources that would be available.

Although good in principle, it adds a lot more burden to the carer in terms of budgeting, decision-making, researching/finding/assessing services
(Female, age 38).

Great in theory, but not sure what options will be out there to 'buy' and how much funding will be there and how far it will go
(Female, age 55).

These sceptical comments were often attributed to previous experiences of disappointment with service provision.

Negative

Negative comments reflected entirely pessimistic beliefs regarding what the introduction of PCAs and IF would mean for people with disabilities and their carers. Several different concerns were raised. One major concern related to the changes being difficult to understand and to navigate.

It sounds confusing, stressful and convoluted
(Female, age 54).

Too radical a change for me at my stage of life – old dogs and new trick, etc.
(Male, age 60).

Some carers also expressed concerns that service providers would increase the price of their services in response to IF.

I think we will see free-market profiteering as a result of the changes
(Female, age 51).

A small minority of respondents indicated that their present circumstances were working well and they did not want to experience any additional burdens.

I am not happy with the idea at all. Leave the system that works alone. You are putting more pressure on families
(Female, age 65).

As well as expressing fears of increased burden on carers, some respondents suggested that these systemic changes were nothing more than a government cost-cutting ploy.

My current fundings (sic) are fully in the hands of [provider]. [Provider] have computer, phone, qualified staff both administrative and field, industry connections and years of experience. You are effectively asking me to take this on as well as my 24/7 caring role. Not interested. Find somewhere else to cost cut
(Male, age 51).

Not only does this final statement represent a concern held by multiple survey respondents, it also illustrates the passion accompanying many such opinions. Although negative comments were in the minority (9.1 per cent of all comments), they do identify major concerns that could inhibit carers' engagement with such services, and therefore provide valuable insight into how PCAs and IF could be either adapted or promoted to alleviate many of these significant concerns.

Discussion

The results of the Carers NSW 2012 Carer Survey suggest that overall perceptions of PCAs and IF were more positive than negative. However, some significant needs were identified in relation to carers' understanding and

willingness to engage with these systemic changes. Perhaps the most telling implication of these results is the need to increase awareness among carers, with less than half having heard of these concepts. It is relevant in this regard to note that more participants indicated an awareness of IF than PCAs. In essence, PCAs provide an overarching contextual approach to disability services, of which IF is a major component. Being aware of the process – that is, IF – without understanding the reasoning behind it – that is, PCAs – could in some way contribute to the sense of scepticism or tentativeness that was evident in many comments. For carers to be fully informed of the changes to the disability service sector, it is imperative for them to understand practical changes and also any theoretically driven policies that dictate how services will be arranged.

Low levels of awareness raise a particular concern in that carers cannot understand the intended benefits without being aware of these changes. It is also possible that a lack of familiarity with the intended shifts in the service landscape could contribute to negative or sceptical views. The importance of familiarity is reflected in the finding that those carers who were familiar with IF were more likely to indicate that they would take the option of managing such funding themselves. These carers were also more likely to be able to identify specific supports they would need, while simultaneously being more likely to suggest that time constraints would prevent them from managing funding themselves. Taken together, these results depict well-informed carers as demonstrating a critical understanding of resources that would be necessary to manage an IF package. In demonstrating such awareness, these carers are those most effectively equipped to make decisions regarding how best to interact with a person-centred system.

As with evaluations of individual budgets in the UK (Glendinning et al. 2008; Moran et al. 2013), results from this survey indicated that older carers were less likely to have positive expectations regarding these reforms. Furthermore, survey results suggested that lower levels of formal education predicted less positive expectations. Previous research has attributed findings such as these to confusion with navigating new systems, and this view is supported by a number of survey comments.

Alternatively, some survey comments suggested carers had experienced previous disappointments with disability support systems. Older carers may have encountered more unfulfilled expectations and disappointing experiences, resulting in less optimistic views regarding any impending systemic changes. Once again, the importance of clear education as to how PCAs and IF can be managed on an individual level is pertinent. These results suggest that older carers and those with lower levels of formal education are more likely to require additional support in deciding the most appropriate approach to interacting with the new system.

Interestingly, expectations regarding the introduction of PCAs and IF did not differ between carers from different geographic regions. This is despite previous research indicating that carers' practical experiences of using IF and accessing services in general are fraught with more difficulties in rural areas than in urban

regions (Dew et al. 2013a; 2013b; Edwards et al. 2009). It must be noted that the present study investigated carers' expectations of the impact of PCAs and IF being introduced to the disability service system, as opposed to practical experiences under these policies. Results may therefore indicate that despite any existing barriers to accessing services, rural carers generally held positive views as to how person-centred principles could benefit their personal situations. It must also be noted that participants' contact with PCAs or IF – for example, through existing initiatives – was not investigated. Therefore, the extent to which expectations were shaped by practical experiences of IF through rural areas, including issues such as those identified by Dew and colleagues (2013b) could not be determined.

Expectations of how the impending changes would impact people with a disability were less positive than those of impacts on carers themselves. While these differences were apparent in the quantitative data, the potential for misalignment between the needs of carers and people with disabilities was not evident within qualitative data. As previously mentioned, these simultaneous needs are important issues to be considered under PCAs (Glendinning et al. 2009), and thus represent a gap in the present survey data. Future research would benefit from qualitatively investigating carers' perceptions of PCAs and IF in relation to their own needs and those of the people they care for. Perceived outcomes for the person with a disability were more likely to predict a carer's intentions towards engaging with IF. This provides valuable insight for policy makers and service providers. In essence, providing a clear understanding of how any given approach will ensure that a person with a disability has their needs better met is a key strategy for promoting engagement with carers. Furthermore, uncertainty as to how these proposed changes could beneficially impact the lives of people with a disability promoted sceptical attitudes among carers. Any proposed change to a service system such as the disability sector is always likely to draw some level of criticism, and comments from this survey show that PCAs and IF are no different. However, the large proportion of comments – over 53 per cent – that reflected some degree of uncertainty, that is, tentative, unsure, or sceptical comments, indicate both the desperate need for more information and the significant potential for improving carers' attitudes towards these new approaches.

Questions were raised regarding the practicalities of IF processes. As found in previous research (for example, Maglajlic et al. 2000; O'Brien 2001; Lord & Hutchison 2003), it is not uncommon for people to hold suspicions of PCAs. Responses ranged from the inquisitive to angry opinions regarding the distribution of funds. These comments demonstrate the severity of the lack of knowledge among these carers, an issue which must be overcome if they are to engage willingly with these systematic changes. Particular areas of concern relate to funding allocation, how much each individual will receive, and how it could be used. Developing an equitable approach to funding allocation within a person-centred system has been previously identified as a major challenge (Lord & Hutchison 2003). The present research strongly indicates the need to reassure carers that IF will provide sufficient funding to meet the needs of those they

care for. Understandably, it seems likely that those carers who believe that these needs will be met, and who feel sufficiently reassured that funding arrangements will be adequate, hold more positive views and demonstrate a more proactive approach to using available options.

Carers also expressed concerns regarding service access. The unknown nature of the impending changes was reflected through carers questioning whether there would be an impact on either the availability or cost of services. While several carers acknowledged that these changes were likely to occur, questions were raised as to how the consequent increase in choice would impact the service market. Positive expectations of market competition and a resulting necessity to provide quality services at a reasonable cost were countered by fears that free market profiteering could occur if service prices were not capped. The freedom of choice that IF is proposed to bring also raised the concern that those service providers offering the best quality would not have the resources to meet their demand fully. While it is difficult to predict accurately how these issues will progress in the IF market place, merit remains in pre-empting potential negative outcomes. Furthermore, any such safeguards should be clearly communicated to affected individuals.

Perhaps the most significant concern raised was carer burden. Particularly among carers who indicated that they already experienced very high demands, the thought of additional work was vehemently opposed. These carers emphasised that they were so consumed with their daily caring tasks that they did not believe they could cope with the additional burdens they perceived with IF. However, these carers described their concerns in a way that suggested they felt they would be forced into taking on additional tasks against their wishes. An important aspect of PCAs is the focus on the individual. In providing choice and control, the choice not to manage funding packages must also be respected. It is therefore essential that this freedom of choice is clearly communicated to people with a disability and their carers, that is, the difference between what they can do and what they must do. While the option exists for them to take on significant responsibilities in directing the spending of funding packages, they are not obliged to do so and may elect for these responsibilities to be outsourced. In this way, the individualisation of PCAs needs to be effectively promoted to reassure carers that they will not be forced into arrangements that do not suit them, the person they care for, and the personal circumstances of both.

Effective communication around the differences between what individuals can do with IF and what they must do may also assist in addressing one of the other sceptical viewpoints described – that these changes are solely a governmental cost-cutting measure. Several carers who expressed beliefs of being forced into unwanted administrative positions felt that they were being placed in such roles so that governmental funding bodies would not have to pay for professionals to take on these responsibilities. If carers were reassured that they would not, in effect, be used as a source of free labour, and that the choice could be made to engage professionals to take on these management roles, the scepticism of perceived cost-cutting may be alleviated. However, the previously outlined

concerns must simultaneously be addressed, namely, that funding would be sufficient, and that appropriate services would be available regardless of whether IF is self-managed or not. Essentially, carers appear to be interested in outcomes rather than processes. Even if they retain the belief that PCAs and IF are cost-cutting measures, the important issue is that they can be reassured that the needs of the person they care for will be met and that they will not be subjected to any additional burdens that they do not choose for themselves.

Limitations of the present sample must also be considered. For example, there was a high representation of Carers NSW members. By nature of their contact with organisational communication, it is likely that they were more informed than the wider carer community of impending policy changes and what the changes could potentially mean in practice. Similarly, members could reasonably be argued to be more likely than non-members to be more proactive in seeking information, having initially signed up to membership, and thus be more inclined to engage with policy implementation. In addition, compared with ABS (2012) data, the present sample reported higher levels of educational attainment and fewer instances of paid employment. This may indicate bias in relation to the present sample's ability to understand policy changes and also the amount of available time to learn about them.

Conclusion

The survey results presented in this paper indicate two main issues regarding the introduction of PCAs and IF: 1) carers' awareness and understanding of these concepts is low; and 2) there are specific areas of concern where carers require comprehensive information and education. While specific details regarding these issues may not be currently available, and may not become clear until systematic rollouts commence, it is nevertheless important to recognise these concerns. When PCAs and IF projects are based on sound planning, positive outcomes have been demonstrated (Lord & Hutchison 2003). Furthermore, it is imperative that effective channels of communication are established to provide answers to these major questions, both in terms of any plans to address concerns, and also how these work out in practice over time. Responding to challenges and criticisms throughout the planning and implementation of these projects is a vital component of ensuring successful transitions and outcomes (Lord & Hutchison 2003). By understanding specific areas in which carers have expressed apprehension, service providers and governments can be better informed as to how to encourage people with disability and their carers to engage with person-centred systems and IF, and how to assist them adequately in negotiating the changing landscape within the disability service sector.

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