Parents, services and system: An exploration of power dynamics in future planning among parent carers for people with disability

Abstract
Interactions between services and families have significant implications for families’ planning for the future needs of a family member who has a disability. However, little research interrogates the implications of these relationships for parent carers’ agency in this planning. This qualitative study explored parents’ experiences with public and not-for-profit services during planning. Findings revealed varied and fluid power dynamics, with attempts by carers to shift to more productive power relations, which carried risks and costs. In a context characterised by systemic constraints, these shifts create an iterative planning process, and highlight the need to support parents to use power productively.

Keywords
Parent carers, services, power, planning, service providers
Background

There is considerable focus in both research and practice on the importance of future planning for adults with disability and their parent carers (e.g. Chou, Lee, Lin, Kröger & Chang, 2009; Gorfin & McLaughlin, 2004; Jokinen & Brown, 2005). This is considered vital as challenges in accessing support and accommodation can result in these families facing options that do not meet their needs or wishes, often as a result of parental death or failing health (Bigby, 2008).

In an environment of service provision in which there are shifts towards individualised funding and consumer direction, the roles of service users and their carers in identifying, choosing, and managing the required supports is increasingly highlighted. Such systems intentionally highlight, and it might be argued assume, a high degree of agency and power on the part of service users and carers. Indeed, the very terminology used in the policy surrounding such schemes highlights the issue of the nature and use of power. Their success rests on the enactment of this agency by families and the development of new kinds of relationships between families and services that facilitate effective use of services.

Therefore a significant dimension of this planning and implementation process, and one which can present challenges to this power and agency, is the interface between families and services, whether government or community-based. Organisations and services act as planning facilitators, service providers, funding providers, and support networks and are vital to planning and implementation. Many non-profit programs also involve families in their management, with parents’ participation important for programs to continue to provide support.

The interface with public services, however, is often cited as problematic. Concerns include issues of information and access (Selepak, 2008) and adequacy of services, with significant levels of unmet need and deficits in specialised disability and other services causing stress for carers (Selepak, 2008; National People with Disabilities and Carer Council (NPDCC), 2009). It has been suggested that despite promises of greater consumer choice and efficiency gains, system changes have resulted in cutbacks, undersupply, and increasing focus on costs and assessment (Spall, McDonald & Zetlin, 2005). Submissions to Australia’s National Disability Strategy Consultation (NPDCC, 2009) similarly highlighted a lack of availability, affordability, choice, and flexibility. The system was described as under-resourced and struggling, endlessly bureaucratic and unresponsive, resulting in sometimes humiliating and frustrating experiences for people with disability and their parents, and failure to provide services and support despite real need. Many submissions praised service staff, who shared consumers’ frustrations. The system was criticised for serving its own needs and those of service organisations, a criticism that has also been echoed in other countries, such as Ireland (Power, 2008).

Indeed, governments increasingly rely on the non-profit sector to address the limitations of the system. While these are often grassroots organisations that are seen as more able to remain connected and to be person-centred and responsive, they can face challenges in meeting these ideals. In their analysis of parents’ experiences with grassroots non-profit services in Ireland, for example, Power and Kenny (2011) identified issues similar to the
criticisms usually levelled at large, bureaucratic organisations and services. These included: lack of information such as whether places are available in programs; decisions made without input; lack of access to suitable places; inability or unwillingness to cater for specific disabilities or issues; geographic restriction and funding rules; and a service-centred rather than person-centred ethos. Therefore non-profit services, including grassroots organisations, face issues in engaging with and providing services to families.

The issues may not all be systemic; a number of studies have identified the direct interface with services and their staff as instrumental. For example, Power (2008) identified the interface with services as characterised by non-supportive interactions and inflexibility. Other studies have found carer-professional relationships to be characterised by disparities in power and knowledge, with parents disempowered, marginalised, and patronised (Mitchell & Sloper, 2001), parents feeling their knowledge and expertise was not adequately valued (Lundebey & Tossebro, 2008; Llewellyn, Gething, Kendig & Cant, 2003), and professionals not understanding the problems older carers faced (Llewellyn et al., 2003). Some parent carers identified by Llewellyn et al. had developed shared understanding and trusting relationships with service agencies and staff; however, these carers were the least common. Other more common types of parent carers chose to go it alone as much as possible, used services only reluctantly, or had no control with services taking complete control of decision making.

Assertive efforts by parents can be essential to the formation of effective partnerships with service providers in which parents have considerable influence (Knox, Parmenter, Atkinson & Yazbeck, 2000). However, in their review of qualitative literature on the perspectives of family carers, in addition to experiences of collaborative, proactive services with high expertise and open communication, Griffith and Hastings (2014) identified a number of themes relating to relationships with services, including challenges relating to bureaucratic processes, ‘us and them’ relationships with services, and issues with poorly trained staff trying to deal with challenging behaviours. This suggests that while approaches of support services are changing, some issues remain.

This is an important issue for future planning. The Disability and Ageing Inquiry in Australia (Senate Community Affairs References Committee, 2011) found that difficulty accessing information and needed services was a barrier to future planning among many ageing parents, with greater availability and quality of information, support for psychosocial, legal and financial planning, and greater housing and support options needed to support planning. Likewise, the interface with professionals can be significant in parents’ approaches to planning. For example, Bibby (2013) conducted a review of literature on future planning for adults with a learning disability who were living with older parents and carers. Their review identified ten barriers to engagement in future planning among these families, which included issues such as a lack of confidence in formal services, a lack of information, fear of the unknown and feeling that it was a painful subject to address, as well as poor relationships with professionals. Bibby identified across the ten themes an overarching concept: the importance of the quality of relationships between families and professionals, highlighting the importance of the professional’s role in helping families work through painful and
difficult issues and address barriers to planning. Therefore concerns about systems and structures that work against planning are of vital importance to addressing the limitations in planning undertaken by parents as they age, and ensuring that those who do engage in planning are supported to enact those plans.

The intersections with services and professionals, whether government or non-profit, and the power relations inherent within these, are therefore vital to understanding and supporting planning among parents. There is a tension evident between relationships with services on the one hand, and on the other, the increasing emphasis on carers’ agency that is part of policy and program processes. This raises questions about their experiences of realising this agency in the context of potentially asymmetrical relationships with service providers and the power relations inherent in these. While there is a growing body of literature exploring the experience of planning and the relationships with services, which describe these relationships broadly and point at issues including power, it does not account for the complexity of the emerging relationships and power dynamics at play. The purpose of this paper is to problematize an approach to power that oversimplifies the understanding of these relationships.

Analysis of power is commonly applied to these kinds of dynamics, particularly within areas such as disability services; however, it has been a challenging and contested concept, with a range of approaches (Tew, 2006). Modernist perspectives of power as something that can be taken up or taken to oneself have been criticised as constructs that define power something that belongs to those already in dominant positions or in possession of the range of resources needed. Structural approaches which see power as a social relation of oppression and subordination have similarly been criticised for promotion of paternalistic approaches to victims of power as oppression, and irrelevance to an understanding of identity as complex and fluid (Tew, 2006). Within such oppressive relationships, service users may find ways to resist or subvert the dominant dynamic. A contrasting perspective is that of co-operative power, in which people use power together, including against oppressive power or to reinforce existing power relations (Tew, 2006).

Tew (2006) suggests that power should be understood as a dynamic that may be oppressive, productive or protective and may operate both top down and bottom up. This is an understanding in which ultimately power is something that one does, rather than something one has, and in which relations may shift between power types. In this sense the power relations between families and services may be understood as more fluid and dynamic than traditional perceptions of service provision might suggest.

Little research literature is available, however, that explores in depth the nature of these relationships in the context of planning and what they mean for parents’ roles in this process. As a result, we are yet to understand empirically how these power relations work. This study explored the issue of future planning among a group of parent carers engaged in exploring options for themselves and their child. While other aspects of the data explored other dimensions of planning, this paper reports on the interactions and experiences families had with services, organisations and government departments during the planning process and
implementation of plans. This paper seeks to understand carers’ experiences and perspectives in negotiating these relationships, with a particular focus on power relations.

Methodology

Procedure

The study adopted a qualitative approach, which used a series of semi-structured interviews with parent carers for a person with disability, and staff of planning programs, including some who filled both carer and staff roles. Families and staff were recruited from planning programs in Queensland, Australia. These programs were services provided by not for profit organisations to assist families specifically with planning for the future care, housing, lifestyle, financial, social, and emotional needs of a person with a disability. The programs were identified through both prior knowledge by the research team of relevant service providers, and a snowballing technique in which additional services to target were identified by respondents.

Participants were contacted by an information letter distributed by the organisations, as well as through organisations’ newsletters, which advertised the opportunity to participate. Participants contacted the researchers directly to indicate their willingness and were provided with detailed information. The information sheet provided to all participants detailed the aims and purpose of the study, details about data collection, and assurance of confidentiality, anonymity, and freedom to withdraw. All participants provided written consent. The study was approved by an ethics committee of The University of Queensland.

Interviews were conducted at a location convenient for the participants, such as in their homes or workplaces, or by telephone. Twenty interviews were conducted, one of which involved two members of a couple, giving a total of 21 respondents. Interviews used a question schedule developed by the researchers. Questions explored issues for the parents relating to their long-term planning for themselves and their children, and their experiences with and willingness to engage with government services and participatory organisations and their programs in different capacities.

Participants

In all 20 women and one man took part, two of whom were staff only and two of whom were both parent carers and staff, who reflected on their experiences in both roles. Respondents were between 39 and 72 years of age. Approximately half of the parents identified as being married or in a de facto relationship, and 60% had post-school education, including undergraduate or postgraduate degrees or diplomas. Two respondents spoke English as an additional language but all could communicate fluently in English. The six respondents who were divorced, single, or widowed were sole carers, whereas those who were married or in de facto relationships shared care; however, this care was frequently unevenly distributed within families. Care needs among respondents’ adult children with disability varied from mild with increasing independence to very high and ongoing. The type of disability included intellectual and physical conditions, including multiple and co-morbid conditions.

Analysis
The interviews were digitally recorded, transcribed, and analysed using NVivo qualitative data management program (QSR International, 2012). Analysis used multiple iterative phases to inductively identify themes and concepts relating to parents’ experiences with services as part of their caring and planning roles (Strauss & Corbin, 1998). The analysis then took a particular focus on the power relationships revealed through the discussions, using Tew’s (2006) understanding of power as a dynamic that may be oppressive, productive or protective, and that may be fluid. With its focus on social work practice, this model might arguably be considered to lack sufficient attention to individual agency among parents. However, it goes beyond a priori assumptions about power as something that some people possess, and helps to bring to the fore the agencies entailed in parent-service relationships that can be central to assumptions about parents’ roles in planning. It was therefore adopted as a framework for understanding parents’ experiences with services, and the implications of this for parents’ agency in the planning process.

Results and Discussion

In the interviews, parents recounted experiences with a range of services and organisations, including government services and departments, service providers, and community organisations. Experiences with organisations were somewhat mixed, particularly for those involved at the management level. A number of parents commented on the relative strengths of different programs they had been involved with. Some programs, they felt, appeared to be stronger at guiding families but did not have the capacity to actually deliver solutions, some did not offer strong guidance to families, and some were stronger at putting solutions in place. The families recounted many positive experiences with non-profit services, including enthusiastic and committed staff, well-designed planning programs, and ongoing practical support.

‘That’s one of the other reasons that I wanted to actually join an association, and why we were involved in [organisation] because I think that to have an organisation that is able to look at it from an organisational point of view, the practical aspects of it and more so, keeping up to date with legislation and also knowing what is available and what’s going on in the community, they are able to provide that and then the families are there to provide that typical family support that people expect from a family....’ (Parent carer)

This practical support gave parents direction in their planning.

‘[Organisation] are really putting in good workshops and good grounding and really helping the families work out how they can put all this into place.’ (Parent carer)

Parents also highlighted the help they had had from individuals within government departments, and services such as the adult guardian, which some had previously been wary of:

‘The one thing I also got out of this expo was a different perspective of the Adult Guardian and the Public Trustee. Because they’ve had a bit of bad press over the years ... I think well at least there is that safety net if you run out of friends and
relatives, the Adult Guardian will still make sure that he is looked after ... And that I found quite reassuring. I stopped viewing them as something evil, and as something comforting and useful and a little bit more trust there.’ (Parent carer)

The findings indicated that the interface with services acted as both a facilitator and challenge to planning.

**Shifting power relations**

The results suggest that parents can be both empowered and active, and passive within disability services and policy and in relation to community based disability organisations. Both past and preferred levels of participation varied among the parents, with some currently heavily involved, including as program staff. Some families were involved with very few organisations and some with multiple organisations, and they were and had been in the past involved in different ways - some only as clients, some in management and some also as staff or volunteers. Preferences for level of involvement were also mixed, with some parents interested in deeper engagement with organisations and others preferring a client role.

**Productive uses of power by parents**

Families’ relationships with services and with community organisations were sometimes conflictual and sometimes collaborative. When power was used productively by parents, this was pursued actively, sometimes through confrontational means. Throughout the data, co-operative and productive uses of power were demonstrated (Tew, 2006).

Such power could be self-perpetuating; for example, active pursuit and formation of networks led to more networks. Networks were seen as an avenue to information and a space for raising issues. Becoming involved with organisations offered these networks, giving a sense of security in having a source of support, information and advice, and ensuring that there was someone to help things run smoothly and prevent the family from missing out on needed support.

‘I guess when the Disabilities Services Act first changed ... the first ten years was pretty horrendous for a lot of people. I know a lot of people fell through the cracks and I think that’s probably now that I think about it, that’s why I wanted [daughter] to be under an umbrella, an association like [organisation], because I think if you’ve got that, there is less chance of falling through the cracks.’ (Parent carer)

Indeed, the lack of involvement in groups that could provide broader networking opportunities was seen as problematic. Historically there had not always been support by professionals for parent networks; indeed, one parent recalled that she had been actively discouraged from forming networks with other parents. The impact that these networks and their absence had was a recurring theme throughout the interviews.

However, simply knowing where to start or where to find information was an initial hurdle for families. Some lacked a connection to services or knowledge about available services, including planning programs and community organisations. Participants recounted
experiences, either their own or those of other parents, of not being aware that programs or organisations existed that could assist them with planning:

‘Well, you just don’t know what’s there, most of the time you don’t even know where to look.’ (Parent carer)

Others recounted finding such programs by chance or information snowballing:

‘...there are other organisations but where do you find out about them? These have all been told to me, [Organisation] was told to me by [Organisation]... and from [Organisation] I’ve learned about [Organisation], [Organisation], [Organisation], and [Organisation].’ (Parent carer)

Word of mouth was a common source of information; however, as has been noted, not all families were connected with groups or networks where such information was commonly shared. Therefore there were costs identified to not seeking productive opportunities for power.

Productive use of power was also demonstrated by parents in attempts to access opportunities and services and in participation in activities to influence policy, and by organisations in their active seeking of avenues for advocacy. For example, one parent reported that they chose to participate in order to ensure that politicians were kept informed:

‘I go and see my local members because I strongly believe whether they are State or Federal, that no politician should have the excuse that they didn’t know that this was the situation. Usually when there is a new member who comes in, I go and see them... And so it only takes one or two visits to them for them to know some of the situations and then when things get to a mess or you really need some help, they can’t say they didn’t know.’ (Parent carer)

It is also interesting to note that for the parents who had been involved in policy making or organisational management, participation tended to be on issues for people with disabilities, rather than issues for carers.

These findings suggest that rather than being passive in the face of powerful others, as much of the literature appears to suggest, parents orient in specific ways to power and engage in processes to shift power in their relationships with services. In examples such as the involvement of parents in the establishment and management of groups and organisations, and the involvement of these organisations in action to develop and provide housing, as well as the attempts by service organisations to engage in collaborative planning, co-operative and productive uses of power were demonstrated (Tew, 2006).

Inability to shift power

On the other hand, some parents did not, or could not, achieve this shift and it was rarely actively promoted by the system. A sense of struggle and frustration was frequently evident in the interviews, particularly for parents who had faced difficulties in identifying or securing appropriate services and housing, despite active efforts on their part. This raises the question of where these barriers to the shifting of power originate.
Lack of responsiveness

It was suggested that planning and implementation were made difficult when service providers had a lack of awareness or understanding of futures planning.

‘...I have never had the opportunity to say how far can we plan ahead? So that it’s not just about what’s happening now, and that’s all.’ (Parent carer)

Inadequate attention to staffing or last minute changes to staffing further created a perception that all programs and organisations were unreliable.

‘...it’s really difficult and so you’ve got families that have had support for years and they’ve put up with it and put with it because there is nothing else, so when you talk to them about doing planning and things like that, it’s just like...is this another empty promise? Yeah, you might do my plans but then you’re going to say goodbye to me and I walk out that door and I go home, or I wake up the next day and there is no one to help me, what do I do next?’ (Planning program staff)

Feelings of frustration or helplessness accompanied multiple setbacks or perceived ‘rejection’ by services, organisations or employers who were not able to provide assistance for their child. One staff member described this experience among some of their clients:

‘...you can try so many different places or try and come up with really creative ways to help that employer employ the person you’re working with, but it doesn’t always work... Sometimes that rejection can just get too hard; ‘don’t want to go through it again, too much, they don’t want me, what can I do?’’ (Planning program staff)

Others felt frustrated with the pace of change and pace of action within the programs they had been involved with.

‘The dream was, our goal was for [organisation] to really support us parents to do what I wanted to do, what I’m doing with this. But year after year after year, all that seemed to keep happening was we had lots of meetings, we had lots of workshops, nothing concrete was happening. We kept saying to [organisation], can’t you help us, but [organisation] kept coming back to us saying ‘well you’re the ones that have to say what you want. You’re the ones that have to put it into place’ when we didn’t even know what we wanted.’ (Parent carer)

Some families further noted that even when planning had been undertaken, a lack of adequate support was available to assist people to remain independent, creating challenges for implementing plans. One parent highlighted the lack of housing options for her son’s future that were suitable for their circumstances, and felt frustrated that the only way to provide options was to abandon him:

‘...the current regime is to dump and run. The only way you can have an independent lifestyle for your person with a disability that I have found through all the research that I’ve done is that you drop him off at either a care organisation or Disability Services and you do not return to pick them up. And I
find that appalling.... and people have walked away from caring and I do know a
couple of families who have... what I notice is that the game plan changes once
they go into care; then [Government department] and the other organisations
come back to you and say what can you do to help us? So you then get the 24/7
support and then they're coming to you to say ‘well do you want to be involved in
your person's life’, because that helps them out.’ (Parent carer)

One respondent reported that their experience of government services was of a lack of
interest in assisting families to access information and services.

‘There is always [Government department] but they tell you nothing, absolutely
nothing. If it’s going to cost them money, they don’t tell you.’ (Parent carer)

Some families also felt some uncertainty about the future availability of services and options
they were considering as part of their planning, and were therefore reluctant to plan too much
in advance.

‘What’s available now is not necessarily going to be available in 15 years and
hopefully things will be better in 15 years, so it’s like having a look but you know,
being cautious about leaving options open with the hope for improvements in
opportunities... It’s a hard one to put your feet in and feel confident about...’
(Parent carer)

In addition, some areas (particularly regional areas) lack a range of services and organisations
for families to access, in addition to limited housing options. Thus, affecting all such
decisions was the availability of options for accommodation and care in their area.

‘Look up here, there is really nothing. So that sort of makes the decision for them;
I believe if there was more opportunity, they would certainly think differently.’
(Planning program staff).

Lack of responsiveness was also demonstrated by other parents who were collaborators in
attempts to use power productively. In the context of parent-run grassroots organisations, for
example, some parents highlighted the challenge of ensuring the workload was distributed,
suggesting that the load tended to be carried by a small number of parents who then may feel
disadvantaged by their position.

‘...I suppose I am now quite fearful of working with other parents because I don’t
want to be the person left... My experience has been with many of the other
parents that they will sit back and leave you to do all the work and not contribute
very much themselves as well, and I suppose that has disillusioned myself as
well.’ (Parent carer)

Bureaucracy

The interface with government departments such as disability services and housing indicated
a prohibitive level of bureaucracy. For example, the system was described as challenging to
negotiate, with a lack of continuity and consistent information, long waiting lists which
required advance knowledge of what their child might need, and difficulty finding
appropriate and desirable housing through the government.
‘I was told if I ever wanted overnight respite for her as an adult that I should be putting her name down now. Children’s Services, it’s about a 3 year wait to get into anywhere that will do an overnight respite.’ (Parent carer)

Parents frequently mentioned the paper work involved in securing and retaining services, including housing, to be a challenge for them. It was suggested that an additional service that organisations could offer was assistance with this paperwork, which was often required on a regular basis. This bureaucracy did not appear to facilitate access to services:

‘What I found really disappointed me about the process, is you fill a lot of forms, you're told one story, circumstances change, but there is no contact from the departments, to let you know that the circumstances have changed. And I found that just appalling and the hurdles that we had to go through to even get him listed as an appropriate candidate for public housing was appalling and I had to argue with them for over 12 months...’ (Parent carer)

The regular frustration of providing information to government departments was sometimes compounded by the nature of the questions themselves:

‘I've heard stories... someone from [Government department] ringing a mother and saying does your child still have Down Syndrome. You know, that kind of thing. Hello?!’ (Planning program staff)

Rejection of parents’ contributions

Indeed, some active parents found themselves actively disempowered by the system they were attempting to navigate, despite their best efforts to shift power. For example, some felt that their ideas and preferences were not heard by the organisations with which they were involved, and one commented on the challenges that can arise in finding support if the family’s preferences or ideas do not fit the ‘mould’ or the government’s or service’s philosophy.

‘...the pie in the sky people who exist, the politically correct people, I just find that everything is so politically correct that my son is not allowed to go with a mate, because the mate might be disabled or all sorts of things like that. I just find that most of the organisations have strict criteria and if you say anything outside that, then they don't represent you. But on the other hand, I don't know of many groups who do actually represent my viewpoint.’ (Parent carer)

Some parents commented that there seemed to be no way to feed information back to organisations or to government services about issues that needed addressing at a policy or service development level, and reported a lack of consultation and collaboration with parents:

‘...that's the way organisations are run, they sort of have their own agenda and this is the way we do things and sometimes they're not really... even though occasionally some organisations will send you something like “are you willing to participate in an interview in relation to the service or fill out feedback forms”, but it's very limited, the questionnaire or something like that. That's very narrow and limited, those questions.’ (Parent carer)
Respondents highlighted the need to work in collaboration and consult with parents on how to approach issues or on planned changes:

‘I think that they need to join with parents, they get more ideas and feedback from parents.’ (Parent carer)

While some were proactive and confident about becoming involved in the political sphere and contacting politicians, others were less so. Some of the reasons for these differences included previous positive or negative experiences with consultations or with government bodies, confidence in undertaking such activities, and access to the skills and resources, time, and energy required. There was a perception among some respondents that families involved in policy and decision making had very little impact on outcomes and that decision makers were not genuinely interested in hearing and acting on the views of families.

‘That’s probably a reason why I’ve resigned from all of that and we’re doing our own thing, we’re going our own way because I think a lot of it was just a waste of time, even though over the years I’m sure parents have made a huge impact but yeah, I don’t really feel like it really gets too far. In the end, it all comes down to dollars as far as government policy is concerned.’ (Parent carer)

Others expressed concern that to make a comment or complaint might have negative consequences for the family’s funding and services.

‘...you don't have a lot of choices and you feel like if you jump up and down and complain, it may affect the service that you receive.’ (Parent carer)

Limitations on power and agency

These issues resonate with the concerns identified in government enquiries and research addressing carers’ experiences (Selepak, 2008; NPDCC, 2009; Llewellyn et al., 2003; Griffith, 2014). Some of these issues presented direct challenges to the productive use of power by parents, for example structural and resource issues such as funding or a lack of individual knowledge resources, as well as fear of consequences inflicted by government or organisational services. These challenges highlight the ways in which both contextual or structural factors, and unequal power relations, can inhibit parents’ agency in productive use of power towards effective future planning.

Examples such as the perceived lack of interest of government service staff in helping parents to find solutions and the control organisations can wield over what services can and should be offered to whom also highlight the power differential that has often been cited, both in the context of carers (Mitchell & Sloper, 2001) and more broadly as an issue in health and social services (Beresford & Branfield, 2006; Cornwall & Shankland, 2008). Unequal relations of power were evident in examples of lack of consultation and consideration of parents’ feedback on services, and in the lack of interest of some service staff in contributing to solutions. What is interesting about such cases is that it is not necessarily health, social work or human service professionals, in this case, demonstrating power through privileging of expertise as is often discussed; rather, staff in a range of service roles wield power in their relationships with parents, even simply the power to disengage from the problem-solving process. As one parent highlighted, for some the decision to relinquish care results in a
reversal of this dynamic; parents then become a potential solution for the service or government department, who actively engage with them around care. In this way parents wield the only form of power available to them.

The findings relating to the disempowerment of parents by and within the system and organisations further raise important questions about who decides which viewpoints are valid and what roles different actors can and should have. Parents’ roles and where they fit within this system appear to be no clearer, nor any more in their control, with the increasing prominence of grassroots and non-profit community-based service providers. Power and Kenny (2011) found that non-profit organisations are at liberty to decide who they service and regarding what issues, and Lundeyb and Tossebro (2008) found experiences of rejection of parents through ‘gatekeeping’ by services. Similarly, these findings suggest these organisations may determine what philosophies or views are ‘appropriate’, what agenda the organisation supports, and what mechanisms for parent input are provided. Parents can thus become marginalised. This represents a shift between productive and limiting forms of power in which members of a group determine which views and perspectives and which needs were included or excluded (Tew, 2006).

Thus despite the collaborative and productive uses of power parents described, these findings resonate with existing literature which often reflects a limiting use of power, or a withholding of power by services or systems. Indeed, it is clear that in some cases carers are not able to shift power because of deep-seated power relationships.

Power between services and system

However, for non-profit services, there is another power dynamic at play – that between the organisation and the government which provides funding. Thus the relationships that challenge power shifts by carers are not dyadic between the carer and service, as often reflected in the literature, but rather reflect a broader contextual dynamic.

For example, the limitations in what is and can be funded and for whom are not always in the organisation’s control, as staff comments highlighted. Thus the ability of the service to meet the needs of parents in planning and caring is determined by the broader system in which all the actors are situated. The service provider is therefore disempowered by the system, through its failure to resource services.

One concern was that the funding and care system did not involve enough flexibility to allow it to adequately support community-based programs to be run in the way they were intended, and to provide the level of support needed by families.

‘...funding kind of falls into categories ... and supporting people to plan for the future and to look at options over a number of years isn’t actually something that gets much funding.’ (Planning program staff)

Planning was not the only aspect of support by organisations that required additional funding:

‘I find that I spend a lot of time just doing general family support .... Making people aware of all these things that they really need to do to be able to benefit from them, or get things that they’re entitled to. I spend a lot of time doing that
but the funding only funds me to do planning, so again an area that is a huge unmet need up here, but there is no funding to pay me to do it or to train somebody else to be able to do it. You know, that's the real problem. Lucky I like to do volunteer work.’ (Planning program staff)

Some challenges for parent-run organisations and groups were also discussed. For example, one respondent suggested that when run only by parents, it is difficult for organisations to be sustainable long-term and that additional support was required.

A range of not for profit organisations were identified as providing representation and advocacy; however, these organisations faced resource limitations for this activity also. Staff of planning services in particular highlighted the importance of other advocacy organisations to better fill this need.

‘...we also realise our own limitations so where it’s a key sort of systems issue we will always link a family with an advocacy organisation like [Organisation] or [Organisation], and get them involved as well... We realise our own limitations, yeah.’ (Planning program staff)

Benefits and costs of shifting power

The data revealed that there were a range of advantages and pitfalls of taking initiative and attempting to shift the power relations. The respondents highlighted important advantages to becoming involved in organisations, policy making and events and initiatives including being more informed, forming networks, creating a safety net, finding additional services and becoming aware of the value of specific services, and ensuring that politicians were informed of the issues. For example, comments such as ‘they are able to provide [up to date information] and then the families are there to provide that typical family support that people expect from a family’ revealed the role of participation in organisations in allowing parents to focus on the family support role.

Similarly, respondents highlighted benefits such as the reassurance that comes from having ‘less chance of falling through the cracks’. This notion of reassurance resonates with the emotional experience of planning, in particular the fear that parents can experience that without their oversight, adequate safeguards and management of their child’s care will not be provided (FitzRoy, 2015). In this sense taking a broader active role provided a proactive and practical approach to combating this fear, suggesting that use of power by carers was also productive of emotional benefits.

For some, the advantages were more abstract, helping to ensure that politicians had no choice but to acknowledge the issues and were informed when the time came to help. Indeed, as Knox et al. (2000) reported, parental assertiveness may be a necessary ingredient in the formation of workable partnerships. Therefore these active and empowered roles adopted by parents, representing productive forms of power, served specific purposes in their care role and in the planning and implementation process. In this sense they were productive of more than just solutions to practical caregiving issues, but also productive of additional resources and supports, shifts in responsibilities, and reassurance.
There were also, however, pitfalls to taking an empowered position and taking initiative within the system. For example, respondents discussed experiences of being rejected by organisations, either for their stance on issues, or simply in the course of attempting to secure services or employment for their son or daughter, as well as risking negative consequences from speaking out, becoming overburdened as active organisational members, and becoming apathetic and disillusioned. Being proactive in regard to co-operative activities with other parents ran the risk of other parents choosing to ‘sit back and leave you to do all the work’. However, the respondents became disillusioned not only with other parents but also with policy makers and the services themselves. Parents were wary, and a common experience was one not only of unreliability and empty promises, but also of rejection when parents attempted to find solutions, access services, and assert their views in organisations. Therefore taking a proactive role within the system and making attempts to shift power relations – whether it be, for example, in decision making, in design of solutions, or in choosing or forming a network to fulfil their requirements – was not always a positive or successful experience. In some cases, it left parents at a greater disadvantage, setting planning and action back a step or even creating additional issues to be addressed.

Further, comments such as ‘We kept saying to [organisation], can’t you help us, but [organisation] kept coming back to us saying well you’re the ones that have to say what you want’ reflect the challenges that can arise when parents are given control over decision making – ostensibly given increased agency in planning - without the information and support they need to effectively do so. Thus practice by collaborators, such as attempts at empowerment without offering required information and support, or a lack of action by collaborators, present important challenges to productive power and risks to planning itself. This also reflects Mitchell and Sloper’s (2001) assertion that participation may not be empowering or fulfilling, particularly given the range of forms ‘participation’ may take and the range of understandings of what this means in practice, as well as the support required for families to participate effectively. As has frequently been highlighted in discussions about user participation in health and social care (see Bochel, Bochel, Somerville & Worley, 2008, for a review), simply having the opportunity to have a voice does not guarantee that service users will be heard, and simply participating does not guarantee influence. These findings also suggest that taking that opportunity may advantage but equally may disadvantage parents.

Therefore the power relationships between parent carers, services, and the system are complex and can be fluid. Parents are often portrayed as disadvantaged and disempowered by an under-resourced, unresponsive service system in which professionals can privilege their own expertise (Mitchell & Sloper, 2001; Llewellyn et al., 2003). Certainly, some of these issues were reflected in the current findings, particularly systemic issues that limit both parents’ own agency and the organisations attempting to provide services. The findings also suggested, however, that these power relationships are not static; parents make attempts to shift power within the system in different ways, either in relation to individual care issues or in relation to broader policy questions, and they enact this in productive ways (Tew, 2006), at times challenged by the limiting practise of power by others as well as practical and systemic
constraints. These attempts at enacting productive power can bring rewards for parents, but also costs, which may have the effect of reinforcing a passive role and further complicating the planning process. It is noteworthy that this is not simply the case within government services, which are often the focus of such criticism. While the data suggested that often the failure of non-profit organisations to meet parents’ needs is the result of inadequate public resourcing, the ways in which organisations are structured and managed and the decisions that are made about parents’ roles within them have significant implications for the use of power. These experiences within non-profit services can be both positive and negative for parents.

Community organisations form an important bridge between families and services in terms of information, advocacy, and assistance in navigating processes. They also provide essential services including housing programs. However, there are serious limitations in the capacity of these organisations and they face a range of challenges, including systemic as well as internal political issues. On a practical level, support for such organisations, and the facilitation of networks between them, is crucial in providing services to assist families with planning and implementation. This support extends to the oft-cited need for adequate resourcing of programs and services, including planning programs that are promoted by the government but not resourced. Further, within participatory planning and housing programs, it is also important that parent-led initiatives are given sufficient guidance and support to ensure sustainability, ability to deliver outcomes, and to ensure that parents do not feel burdened by their position within the program. Even for programs without parental management, however, consultation with parents and involvement of clients and their parents in decisions that affect services is vital. Further research should address not only how parents can effectively engage in shifts towards productive power with and within these organisations, but how organisations can support families in a planning landscape of uncertainty and shifting dynamics.

Limitations

It must be noted that this was a small scale study with a limited sample within one geographic context. Of note is the gender bias in the sample; a different gender balance may have influenced the findings, and the reflections about power relations drawn from them. Future research should expand on this work to explore these issues in other jurisdictions and contexts, with a larger and more diverse sample of respondents. A larger sample would also allow for exploration of the extent to which parent and staff perspectives converge. Despite these limitations, however, this paper offers important insights into the nature of power relations in the planning process, and their implications for parents’ roles.

Conclusions

This paper has explored the nuances of power relations between parent carers and services through the processes of planning. Drawing from an exploration at the experiential level of parents, the findings point to the different levels of power dynamics and the ways in which parents orient to power. In this way they problematise approaches in both the literature and in emerging policies that assume static power relations, which serve either the carer and client, or the service.
While carers’ experiences had practical implications for planning, they also highlighted that there are a range of facilitators and limitations to power for parents within the system, and parents take different positions of power, sometimes actively and through confrontational means. Examples of both productive and limiting power relations (Tew, 2006) were evident in the interviews. Therefore parent carers’ relationships with organisations and services are characterised by different power dynamics and parents orient to power in active and productive ways. However, while playing an active role in planning and in organisations and political arenas can carry benefits for parent carers, these activities are no guarantee of productive power relations. Further, there are costs to these attempts to use power productively. Therefore both using and not using power to mitigate future risks for their child carry risks for parents within the system. Organisations can play an important role in empowering parents to plan and to navigate a disempowering system, but themselves also need support and resources to do this, as the power dynamics at play operate within a broader context that constrains organisational supports.

Throughout the planning process, therefore, parents, services and the broader system are engaged in a power dynamic that directly and indirectly impacts on the ability of parents to effectively engage in planning. The shifts in power between these actors occur in the context of resource constraints and embedded assumptions about the roles of each actor. This creates an environment in which planning is often iterative rather than a clear process, involving acceptance of uncertainty while engaging in reflection and development of a vision for the future.

In all the paper raises questions regarding agency and underpinning static conceptions of power. In so doing it invites further consideration of how planning processes and practices can incorporate more overt awareness of and preparation for situations characterised by uncertainty and complexity, and power relations that are dynamic and unpredictable, in order to support parents to use power productively. In a service environment increasingly characterised by expectations of power and agency wielded by service users and their carers, the complex reality of these dynamics highlights significant challenges in realising the potential of consumer-directed approaches to care planning and management. There is a clear need for research that explores these complexities and dynamics in the context of planning, in order to inform the development of practice.
References


