Models of Governance in Long-Term Disability Care and Support:
A framework for assessing and reforming social policy

Paul Henman & Michele Foster

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Biographies

Dr Paul Henman is a senior lecturer in social policy and Director of the Social Policy Unit at the University of Queensland. His main research interest is in the nexus between social policy, public administration and information technology. Paul's substantive policy interests are in social security and welfare, as well as living standards and the costs of raising children. He typically combines original empirical inquiry with social theoretical insight. His most recent books are *Administering Welfare Reform: International Transformations in Welfare Governance* (Policy, 2006; edited with Menno Fenger) and *E-government: Reconfigurations in Public Administration, Policy and Power* (Palgrave Macmillan, 2010).

Dr Michele Foster is a Senior Lecturer in the Social Policy Unit, School of Social Work and Human Services, University of Queensland. Her primary research interest is in the area of applied health policy and health services research, with an emphasis on policy implementation, professional decision-making and patient experience. She also has a strong track record in the area of social policy and service provision for adults with acquired disability following catastrophic injury, trauma and serious illness. Dr Foster has published widely in the areas of health policy, health services research, disability and rehabilitation. She is co-author of *Health Care Practice in Australia* (2008), published by Oxford University Press and was a contributor to the first World Health Organization's (WHO) *World Report on Disability* (2011).

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Paul Henman & Michele Foster
Social Policy Unit
Faculty of Social and Behavioural Sciences
University of Queensland
p.henman@uq.edu.au   m.foster@social.uq.edu.au

Abstract

Over the last three decades, the financing and provision of care and support services for disabled adults has undergone profound and ongoing change in advanced welfare states. Despite national variations in contemporary care and support systems, common characteristics of the 'mixed economy of care' are its complexity, diversity and inequality of outcomes. Different policy and service delivery models for the delivery of care and support services have been developed, implemented and promoted as ways in which to enhance the governance of these services. In helping to advance research and evaluation into these varied policy and service delivery models, this paper outlines four distinct ideal type models of governance of care and support: uncoordinated; case manager coordinated; dwelling coordinated and user coordinated. In presenting each governance model, their relative strengths and weaknesses are articulated. Each governance model is further illustrated by empirical case studies drawn from research conducted in Australia with adults with an acquired disability. Such models provide a conceptual, analytical and methodological tool for critically thinking about and engaging with policy debate and research into this domain.

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'Governance' is a concept of substance. It has gravity and importance, and in the last decade it has proliferated as a topic of much academic and practical importance.[1] Yet, the practice of managing, administering and governing, which is what governance is about, has long existed. The recent 'governance' phenomenon is arguably reflective of a broader redefining of governance in contemporary welfare states, and a heightened anxiety about how best to govern. Pragmatic debates have focused on what modes and models of governance to utilise, which are most efficient, which best reflect the socio-political culture of a nation, and which can be located within the political, economic and legal context in which they operate. In contrast, reformist intensions have focused on the contextual realities that can be reformulated to install new governance modes and models.

Concerns and questions about governance also reflect (often unrecognised and unspoken) anxieties about ungovernability and failures of governance. If governance is not 'right' what are the consequences of failure? Who will be affected and how? Thus, governance is also about risk and responsibility and its management and redistribution. Thus, the question of governance, governability and governance failure are of upmost importance, as the 2008-10 global financial crisis and recession, and global climate change well illustrate. Not only do they demonstrate the dramatic consequences of governance failure, but also the difficulty of governance and how to make governance work, especially in domains of great complexity and multiple actors.

Disability is an area of particular governance complexity and anxiety. The immense diversity of impairment is accentuated further by the unique social, policy and institutional structures and processes within which personal impairment is experienced. Moreover, these often produce social exclusion, neglect and disadvantage. Such issues generate concomitant questions for welfare states in terms of responding to and governing socio-economic disparities and difference. This involves questions of not only the governance of care and support services, its finance and management, but also the governance of disability itself.

In the last decade, the governance of disability services has undergone considerable analysis, deliberation and reform in most OECD countries. New organisational arrangements have been installed and new funding regimes instituted. These developments respond to particular issues and problems within disability services, including increased demand and rising unmet demand for services and increasing complexity of impairment and co-morbidities. They are also part of a wider policy and service reform agenda arising from two intersecting reform agendas. First, New Public Management has involved the installation of business approaches to public sector management, market models of service delivery, and management to outcomes and performance measurement (Lane, 2000; McLaughlin, Osborne, & Ferlie, 2002; Pollitt, 1993). Second, the citizen or service user rights movements has sought to shape policy and service delivery around service users (not institutions) who are conceptualised as active, entrepreneurial agents with rights, ideally resulting in more responsive and holistic service delivery (Clarke & Newman, 2007; Needham, 2011a).

These public service reforms have generated a continuous flurry of policy and service innovations for the provision of services for disable people. As detailed below, these have resulted in shifts from deinstitutionalisation to community care and from organisational to personalised funding. The

governance of care and support services has varied accordingly, framed and influenced by different institutional contexts and ideological persuasions. However, a complex, often uncoordinated, even ungovernable, mixed economy of care is a common feature. Still, despite this vigorous reform, according to WHO (2011) disabled people still experience poor access to services, and much poorer outcomes than the wider community in which they reside, which is suggestive of continuing governance failure. For this reason it is pertinent to consider governance from a conceptual perspective from which we can begin to understand the different ways in which governance operates as distinct models, and conceptually tease out what these different governance models might mean in terms of individuals with a disability and governments, their relative strengths and weaknesses, and the occasions in which they may fail.

The purpose of this paper is thus firstly conceptual in that it seeks to identify and delineate between different ideal typical governance models of care and support services, and to logically determine the relative strengths and weaknesses of these various governance models. This conceptual work is directed towards analytical and methodological innovation. Analytically, the models enable empirical data to be analysed and categorised according to the models, as is illustrated using research conducted by the authors later in this paper. This helps to demonstrate and tease out the strengths and weaknesses conceptually identified. As argued in the paper's conclusion, the governance models also enable new methodological approaches to conducting and analysing disability services and policy.

To this end, the paper is structured in four parts. The first section briefly presents the three main modes of governance articulated in the governance literature – bureaucratic, market and network – and the relative strengths and weaknesses of these broad governance modes. This conceptual work from the governance literature fruitfully demonstrates that no one mode is perfect, and highlights the circumstances in which governance failure can arise. The second section then summarises key shifts in disability policy and service delivery in modern welfare states in relation to their governance arrangements. Arising from this review, the third section proposes four ideal typical models of disability governance and assesses each of their relative strengths, weaknesses and occasions for governance failure. In order to demonstrate the experience of moving from conceptual purity to research application, each governance model is applied to empirical data from an Australian study being conducted by the authors. By applying each conceptual model to empirical data we seek to emphasise the key elements of the different governance models and to provide a basis for considering the strengths and weaknesses of the models and how these may arise in practice. This application thus demonstrates the methodological and analytical usefulness of the models of governance to subsequent research, that reality is more complex than conceptual models, and that the empirical data illustrate and reinforce the conceptual reasoning in the previous section. The paper concludes by reflecting on how the models of disability governance can further policy research, evaluation and development particularly in an international context.

The empirical data reported below is based on a research project being conducted by the authors on the management and financing of lifetime care and support as a result of an acquired disability in the Australian State of Queensland. The project firstly involved a mapping of the institutional policy and service context of disability services. Secondly, it involved case studies of 25 adults with high care and support needs as a result of an acquired brain injury, spinal cord injury, Huntington's disease, Multiple Sclerosis, or Motor Neuron Disease. Each case study involved separate interviews with the adult receiving care services, a family or friend, a care service provider and (where appropriate) a

financial manager about the disability services governance and financial arrangements in that case, and the experience of their provision.[2] A reliable comparative summative measure of each individual's service experience and areas of unmet need was also captured at interview by using a modified version of the Service Obstacles Scale (SOS) (Kreutzer, 2000).

Modes of governance

'Governance' is an overloaded term. It is used in a variety of ways for different purposes. Despite the inherent ambiguity within governance discourses, the governance literature generally recognise and discern three different ideal models of governance or modes of coordination – governance by market, governance by bureaucracy, and governance by network. In the context of examining economic development, Jessop respectively describes these distinct models as 'the anarchy of the exchange, organizational hierarchy, and self-organizing "heterarchy"' (1998, p. 29). Governance through the market is achieved by the self-organizing 'invisible hand' through competition in prices and maximising of profits. Governance through bureaucracies is achieved through rules and regulations. Network governance is through partnerships, dialogue and collaboration. A broad brush history of the governance of Anglophone capitalist welfare states in the second half of the twentieth century would observe bureaucratic governance ambitions of the post World War period being re-imagined as market governance from the mid-1970s, which is then supplanted by network governance in the closing years of the century. Each of these shifts in governance involves a search for new governance capacities and enhanced governability as well as a response to observed governance failures.

The search by governments for new and improved governance models in relation to previous modes of governance is an important process in policy learning. While some advocates may be in search of the 'perfect' governance model, and indeed, this seems to be the underlying thinking in advocates of network or third way approaches to government, Jessop importantly reminds us that there is not one perfect approach to providing public services. All governance models are subject to failure. Jessop articulation of governance failure is based on the objectives inherent or embedded in governance model. Thus,

> "Market failure is usually seen as the failure of markets to provide economically efficient allocations in and through pursuit of monetarized private interests… State failure is a failure to achieve substantive political objectives defined as in the public interest and enforced as necessity against particular interests" (1998, p. 38).

Further, network governance fails when participating organisations fail to agree on the objectives or fail to effectively communicate. However, it is also possible to consider instances of governance failure by external objectives, such as improving the health of citizens, producing well educated students, or providing quality care that carers are satisfied with.

Transformations in disability governance

The governance of care and support services in Anglophone welfare states can be examined in the light of these governance developments, at least at a broad brush. With the development of the welfare state during the twentieth century, governments typically created bureaucratic and institutional responses to people with disability or mental illness, housing them in large purpose-built institutions (or asylums) separated away from society at large. From around the 1970s, policy responses began to change as a result of disability rights movements and service attitudes. Under the

'deinstitutionalisation' policy operating in many Western countries, disabled people or mental illness began to be increasingly housed within the community, including their own homes, or small-scale special built community-based facilities. Initially the focus was on people with lower levels of disability or mental health, but increasingly this has occurred to embrace a wider range of disability and mental health capacities (Brunton, 2003; Emerson, 2004; MacKinnon & Coleborne, 2003; Young & Ashman, 2004). While there is great variation in the timing, nature, extent and populations experiencing deinstitutionalisation, and the effectiveness of this process, it is a shared policy movement and practice across the Western world (Mansell & Ericsson, 1996).

This instigation and operation of deinstitutionalisation necessitated new modes and models of delivering and financing services. While some people resided in their homes cared for by family members, others resided independently in homes, while others lived in community based facilities including aged care nursing homes. Financing and operationalising these different dwelling situations required different policy settings, such as supporting families' informal care provision and providing respite, funding formal care services to deliver care in people's homes, and funding the establishment and operation of purpose-built facilities or nursing homes. While some community-based facilities have been government owned and run, often they are managed by not-for-profit organisations (typically church based) or for-profit businesses. In short, what was dominated by the delivery of care through state bureaucratic institutions, transformed via deinstitutionalisation into a 'mixed economy of care' delivered through a mix of informal and market, quasi-market or partnership (ie network) governance mechanisms (Le Grand, 1991; Lewis, 1993; Wistow, Knapp, Hardy, & Allen, 1994; Wistow et al., 1996).

The deinstitutionalisation process has yielded a complex assemblage of care and support. While instigated by ideals of humanisation and equality of all persons, a criticism that has emerged in the last decade is that care and support services have been driven and directed by providers, rather than the service user. This critique has coincided with a wider political discourse about citizens and consumer rights (Clarke & Newman, 2007), active citizens and theories of individualization (Bauman, 2001; Beck & Beck-Gernsheim, 2002). As a result, more recent developments in care provision have focused on individualised, personalised or holistic care (Needham, 2011b; Yeatman, 2004, 2009). Again, the governance mechanisms have varied from determining individualised packages of care for a specific individual which are managed and delivered by an organisation and funded by government, to the government financing of individuals to purchase their pre-determined care needs on the open market (Blyth & Garnder, 2007; Duffy, Waters, & Glasby, 2010; Glasby, Le Grand, & Duffy, 2009; Caroline Glendinning & Kemp, 2006; Lord & Hutchison, 2010; Prideaux, Roulstone, Harris, & Barnes, 2009; Priestley et al., 2007).

Alongside this organisational restructuring is a parallel complexity in financing care and support services for disabled people. Following the logic and model of insurance, from which social insurance emerged, insurance models have long been in place for individuals who have acquired their disabilities through workplace, automobile or medical accidents (Anderson, Heaton, & Carroll, 2010; Defert, 1991; Fishback & Kantor, 2000). These insurance systems set up a financing mechanism to compensate people for acquired disabilities from accidents, thereby establishing a delineation between disabled people who are not covered by insurance compensation systems and those who are. Moreover, the complexity of insurance financing for acquired disabilities is also complex with different sectors covered (workplace, automobile or medical accidents), as well as a

mixture of private and state insurance providers, sometimes as monopoly providers and others within a regulated or deregulated market.

The mixed economy of care has resulted in a highly complex assemblage of policies, practices and financing arrangements. The governance of services has been multiple and complex, often with no overarching governance mechanism in place. Arguably, the complexity of care and support for disabled people is also a result of the complexity of disability and impairment. Disability is not a cohesive experience. Rather there is a great variety of experiences which are related to the individual intellectual, physical, psychiatric impairments, but which are also embedded within and impacted by specific social contexts, physical environments and disability practices (Thomas 2007). This in turn means there are varying impacts on employment and/or education and thus income, personal care, domestic help, health needs, accommodation, transport and recreation. Perhaps unsurprisingly the governance of care and support services is often segmented along different domains. Social protection systems provide private income, health systems provide rehabilitation and therapeutic services, accommodation and transport services are further contained in two other segments, and so on.

This two-fold complexity in the governance of disability – first, the involvement in state, for profit businesses, non-government not-for-profit organisations, and informal private provision, and second, the diversity of domains in which support for disabled people – constitutes a domain that is potentially ungovernable and subject to governance failure. Indeed, a recent inquiry described the Australian situation as follows: "The current disability support system is underfunded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports" (Productivity Commission, 2011, p. 2).

At the heart of the matter are the needs of the disabled person to bring these various domains, institutions, individuals (professionals, paraprofessionals, family and friends) and finances together to support their functioning, activity and participation needs. Taking the perspective of the disabled person these various threads must be woven together to form a fabric of support seamlessly enmeshed into one's life activities and aspirations. This is a key governance issue. Traditionally, the perspective has been from government or from care and support service organisations.

The potentially problematic 'mixed economy of care' has generated a search few new policy setting and governance arrangements, but is an activity with a long history. In order to critically engage in this policy analysis and development process, this paper seeks to conceptually delineate different modes of care and support governance. It is through the identification of different governance models that their relative strengths and weaknesses, the occasions when they operate well and operate poorly, can be both conceptually and empirically analysed. Thus, the key analytical objective of this paper is how the disparate fragments of care and support can get woven together, what models can be discerned and what are the relative strengths and weaknesses of each model.

Models of care and support governance

Drawing on the above literature on care and support governance we propose four ideal typical models of care and support governance: uncoordinated; case manager coordinated; dwelling coordinated and user coordinated.[3] Table 1 summarises the characteristics of each governance model

which is described in more detail below. These models are ideal types to delineate the different modes of thinking in the literature and policy, and as such enable a comparative analysis. It is acknowledged that reality is far more complex. To demonstrate this, we illustrate each governance model with a real case study of an adult individual with a high level of long-term care and support need as a result of an acquired disability. As discussed above, each case study is drawn from research conducted by the authors. These empirical case studies, which use pseudonyms, help to illustrate the greater complexity of lived experience of disabled people, but also the relative strengths and weaknesses of the particular governance model.

Table 1: Four models of disability service governance

| Model	Uncoordinated	Caseworker governance	Dwelling based governance	Individual governance
Characteristics	Separately-provided services are provided *to* the individual uncoordinated	Services are coordinated by a case worker	Services are coordinated by accommodation facility	Services are coordinated by the individual (or family member)
Funding	Various	'Pooled' into case worker	Varied into facility	Single from individual budget
Example	Default	Individual budgets; disability insurance	Community based care	English direct payments
Strengths	Individual at centre, nominally in control	Co-ordinated Person centred; holistic; advocate; reduces stress; clear accountability	Co-ordination is somewhat person centred; reduces stress; economies of scale	Personal autonomy & choice; Innovative markets of care; clear accountability
Weaknesses	Individual has services done to them; little autonomy; fragmented; diffuse accountability	Depends on case worker; lack of choice, or control; gatekeeper	Depends on dwelling; dwelling centred; lack of choice/ autonomy; hard to change; gatekeeper	Individual risk & responsibility; adequate financing; market
Governance failure	Segmented; complex; no autonomy; lack of finances	Lack of choice, or control; lack of finances	Poor dwelling arrangements; lack of choice, or control; lack of finances	Inability to manage funds; market failure; lack of awareness of possible services; market failure

Uncoordinated governance model

The *uncoordinated model* of care and support governance is characterised by an individual receiving services that they are deemed to need and have eligibility to receive. The services are managed and controlled by the organisations that deliver the services, with no input from the individual. This is diagrammatically illustrated in the left hand box of Figure 1[4], where the individual is the central circular node 'IND'. The square nodes surrounding the individual represent the various service organisations providing distinct services, namely personal care (PC), domestic help (DH), respite

(Res), accommodation (Acc), disability-related aids and equipments (Aids) and income ($). No doubt other services could be included, such as transportation, rehabilitation and therapy, information and advocacy, and community engagement.

This ideal type of governance is characterised by individuals having services done to them (as illustrated by the ingoing arrows), and the notion that different organisations provide different types of services funded by different funding streams. It is a default model in that there is an absence of service coordination. The key strengths of this model are that the individual is at the centre and the rationale for the services, and that they are nominally in control. The potential weaknesses of the model are that the individual actually has services done to them, with little autonomy, and that services are fragmented, complex and uncoordinated. Accountability to both individual and government is diffuse and potentially problematic. Governance failure is manifest when the services fail to address the person's needs and can arise as a result of several inter-related factors. It can occur as a result of lack of financing of services, the segmented or complex service arrangement, poor coordination of services, services driven by organisational rather than personal needs, or no autonomy to shape care for their own needs and life objectives.

Figure 1: Uncoordinated governance of care and support
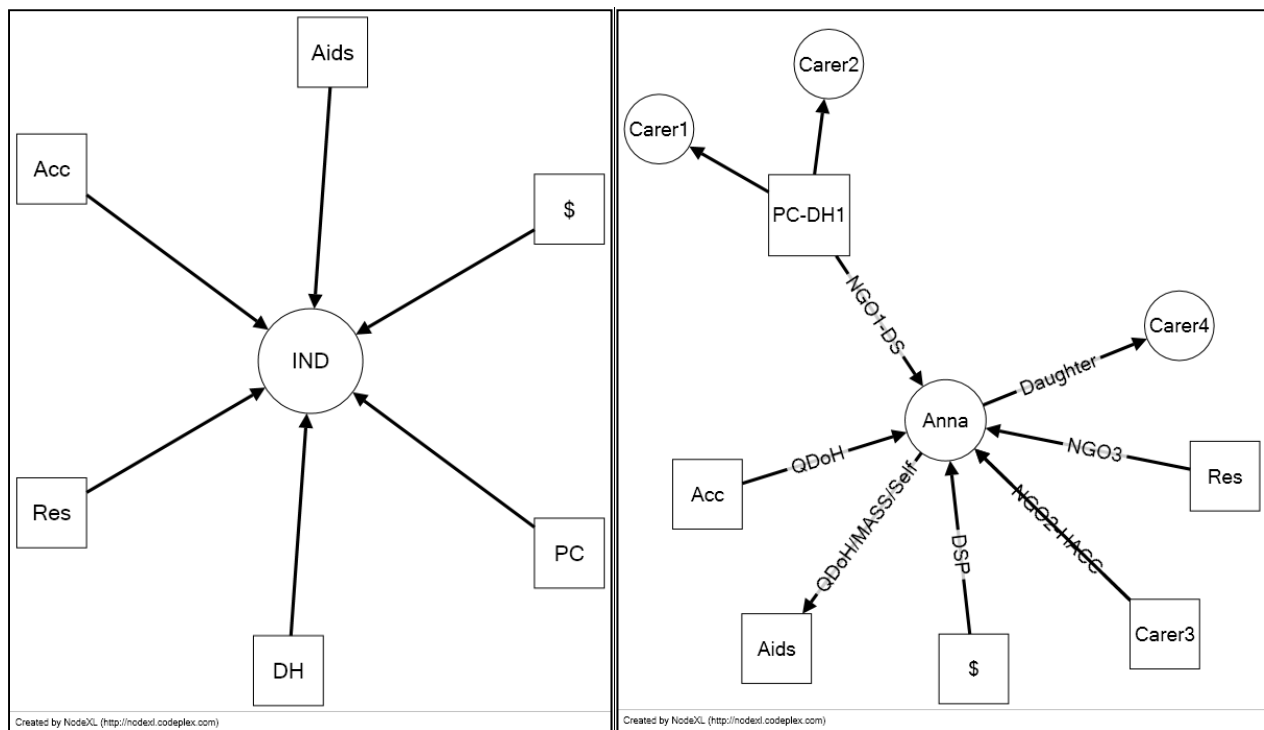
The realities of this governance model can be depicted by an empirical case study (Figure 1, right hand box). 'Anna' is a 47 year old single woman with Huntington's disease who has four children. Anna lives at home in a public housing dwelling with her youngest child of 17 years who assists her mother constantly. As illustrated in the Figure, Anna has four carers, two coordinated from a non-government organisation (NGO) which provides both personal care and domestic help. These services are funded by the organisation and the state disability organisation (as demonstrated by the tag 'NGO1-DS' on the inwards arrow). A second organisation comes three times per week to assist

with showering and one morning a week to provide domestic assistance. Anna's daughter is her fourth carer, and a third NGO provides respite for her daughter. Anna's income is from the means-tested Australian government Disability Support Pension, and her aids and equipment have been initiated by herself and variously funded by herself, the Queensland Department of Housing and the government Medical Aids Subsidy Scheme (MASS).

In this example, Anna finds the NGO1 carer coordinator "helpful." She is especially satisfied with her main carer: "If there is anything going on, she will fix it. She's good", and this carer decides for Anna "because I can't make up my mind anymore". However, the care is uncoordinated and involves many people. Anna's experience is there are "lots of different people" coming to her home and it "gets confusing" and Anna feels "terrible." The care and support arrangement in this individual example is seemingly precarious, as depicted by the Anna's expression "I'd be buggered" without her main carer, or daughter and perception of insufficient care hours from NGO1 for cooking and washing, due to insufficient funds: "It's a big problem." In this example, Anna is not getting help on weekends, but relies on her daughter. As Anna's daughter only has learners' drivers permit, Anna relies on her main carer for transportation. Anna also lacks the financial resources to pay personally for medical rehabilitation and disability-related services, despite the perceived need for physiotherapy for balance and back pain issues. In responding to the Services Obstacles Scale, Anna reported agreement with the statements "I have little confidence in the quality of care now being provided" and "I don't know if there are good care and support resources in my community", which can be interpreted as reflecting the arising from the complexity and lack of autonomy of her situation. However, Anna reported satisfaction with the amount of professional help and support, transportation, and money for disability related services, which may not be entirely consistent with her descriptive account. Anna's responses on the Services Obstacles Scale reinforced these observations. She agreed with the following statements: 'I am dissatisfied with the amount of professional help and services being provided"; "Transportation is a major obstacle toward getting enough help"; "Lack of money to pay for medical, rehabilitation, and injury related services is a major problem"; and "For my problems, there are very few resources in the community". Anna did, however, express confidence in the quality of care she received and her knowledge of care and support services in the community.

Anna's case study illustrates a number of characteristics of the uncoordinated governance model of disability services. The complexity of multiple people and funding sources is problematic, confusing and generates dissatisfaction. Because care and support is uncoordinated it fails to maximise the effects of the services to the benefit of the individual, and there is little autonomy to improve this. Funding clearly limits what level of service is achievable. As a result of funding and lack of autonomy, the individual has very little capacity to reduce the precarious nature of her support infrastructure.

Caseworker governance model

One policy and service delivery response to the lack of coordination has been to install case workers to manage and coordinate an individual's case and support needs. This is illustrated in the left hand box of Figure 2. The outward going arrows from the caseworker (CW) to the care and support services indicate that the caseworker is initiating and coordinating them on behalf of the individual who receives them (inward pointing arrow to IND). Funding for these services can occur either

through the diverse range of funding streams (as with the uncoordinated model). Alternatively, funding can be directly provided to the caseworker with which to 'purchase' services on behalf of the individual. Individual care packages or budgets managed by a caseworker are examples of this model, as is disability insurance models whereby compensation funding is provided to a caseworker. A clear strength of this model is the services are actively coordinated by someone with knowledge of the individual's needs and the care and support service sector, who can act as an advocate for the individual. It is more likely to be person-centred, with more holistic service provision a key feature of the design. Such coordination is also likely to avoid the stress on the individual about the organisation and adequacy of care. It also provides a locus of accountability to both the individual and government for the quality of care and finances. Negatives could include that the quality of the services is partly based on the quality of the caseworker, and this coordination role can lead to a lack of individual choice and control or autonomy, especially if the caseworker acts as a gatekeeper. These are the situations that can lead to the failure of this governance model, as well as lack of funding for services (see Table 1).

Figure 2: Caseworker coordinated governance of care and support

Created by NodeXL (http://nodexl.codeplex.com)
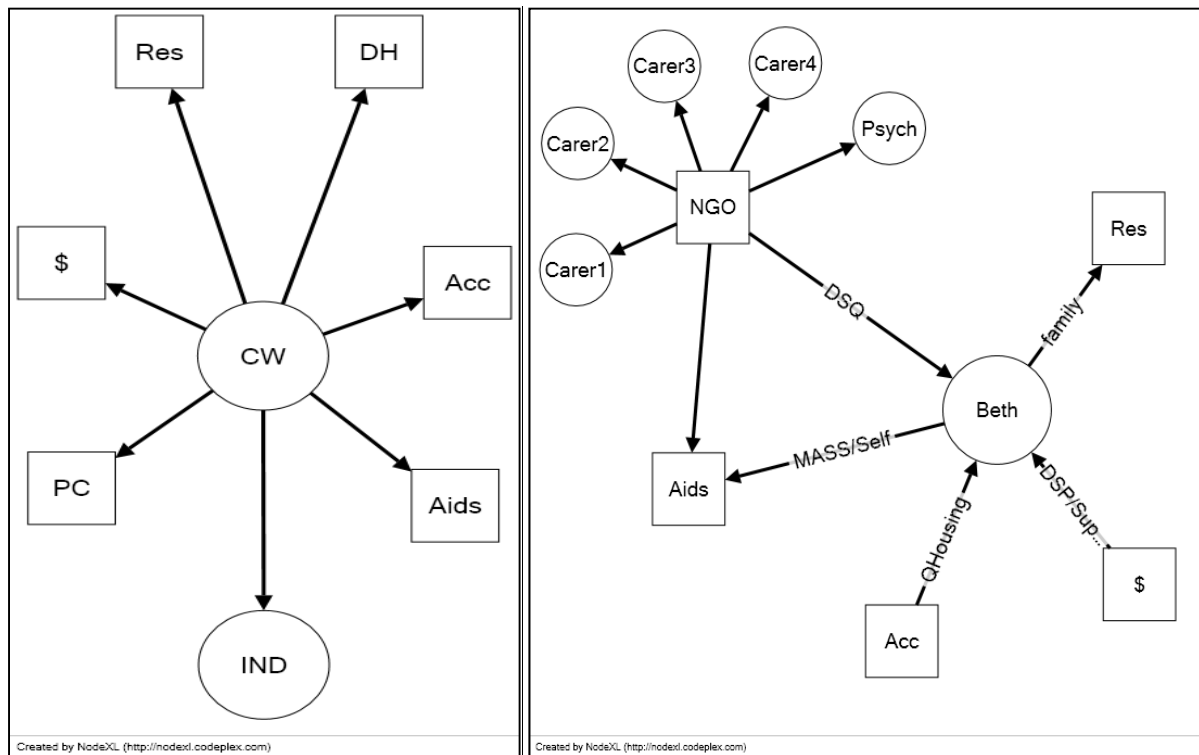
The right-hand side of Figure 2 illustrates the caseworker coordinated model with the case study of 'Beth', aged 47 with a spinal cord injury. Beth lives in public housing, with care and support coordinated by a dedicated spinal cord injury NGO. The services coordinated by this organisation are funded under a special Queensland government program, Spinal Cord Injury Response (SCIR). As is illustrated in the Figure, the NGO coordinates four rotating carers who come three times per day, for up to eight and a half hours at a time, and personal carers are arranged for holidays. Psychological counselling was also accessed; however, funding for this service was presumably capped as Beth was unable to access psychology services on an ongoing basis. Although Beth perceived a need for more

therapeutic services, including psychology, she was not able to afford private physiotherapy, psychology and psychiatry services. By contrast, Beth's air-conditioner was funded from unused carer hours for one year, and an emergency grant of $2000 towards her fully adjustable bed was funded by the same organisation. The government Medical Aids Subsidy Scheme contributed to a power-assist wheelchair, to which Beth personally contributed from her own funds. Personal income in this example comes from a partial government Disability Support Pension as well as from private superannuation.

The caseworker clearly plays an important role in the providing Beth's services, but Beth is also active in her own care governance. Beth and her caseworker negotiate hard for what Beth regards she needs and "deserves". She interviews and selects her carers, although perceives the quality of staff is not high, as it "isn't the top shelf job that you are getting". While Beth is satisfied with the level of personal care and domestic support she receives, she dislikes the intrusion of such carers – "it drives me insane" – and is not satisfied with having carers in the house as she feels that they are in control and not her. She feels "railroaded" by some of them. High staff turnover of carer workers and psychologists is also an area of dissatisfaction. While Beth has an assessed package of care that is managed by her case worker, the NGO has discretion over the expenditure of unused care hours at the end of the year. Interestingly, while personal care hours allocated to Beth might be unused at the end of the year, these are not automatically rolled over to her. Rather, the organisation decides in consultation with their government funding agency. This is perceived as unfair by Beth, "If they are your hours, you should be allowed to have access to them for equipment and things that you may need". In her responses to the Services Obstacles Scale, Beth strongly agreed that "lack of money" for services is a major problem, and agreed that there were "very few [support] resources in [her] community". She did, however express satisfaction with transportation to access help.

This case illustrates the potential strength of an active caseworker in making this model of governance operate effectively. Yet is also illustrates that caseworkers within organisations can use their position as caseworkers for several clients to shift resources among them to achieve what they perceive as fair and equitable, even if not in the best interests of a specific individual. The case also reinforces the observation that adequate resourcing is essential for any governance model of care and support services to operate successfully.

Dwelling based governance model

As already noted, appropriate accommodation for disabled people has been a central policy concern in recent times, and resulted in a shift from institutionalised care to community based care, either in one's home or in community facilities. The provision of care and support in specialised community-based facilities demarcates the third governance model of care and support (see left hand side of Figure 3). In many respects this model mirrors that of the caseworker governance model. However, in this model, the responsibility for coordinating services lies with the dwelling in which the individual resides, not a caseworker. This is illustrated by the arrows going outwards from 'Acc' to the various care and support services and to the individual (IND). Funding of this model is varied, but is pooled into the dwelling either for each individual or collectively for all residents in the facility. Potential strengths include the coordination of services on behalf of the individual, thereby reducing stress and worry, as well as clear locale of accountability. Another likely benefit of this model is that is enables economies of scale through the coordination and provision of services to

multiple people residing in the one dwelling. While service coordination can be person-focused, a possible weakness is that this person-focus is balanced by the overall dwelling needs and those of other residents. In this respect, the governance model may involve reduced personal choice and autonomy, with the dwelling acting as a gatekeeper, and the capacity to change dwellings is typically quite difficult and onerous. The model is likely to lead to failure when the dwelling and its management is of poor quality and resourcing is inadequate (see Table 1).

Figure 3: Dwelling based governance of care and support
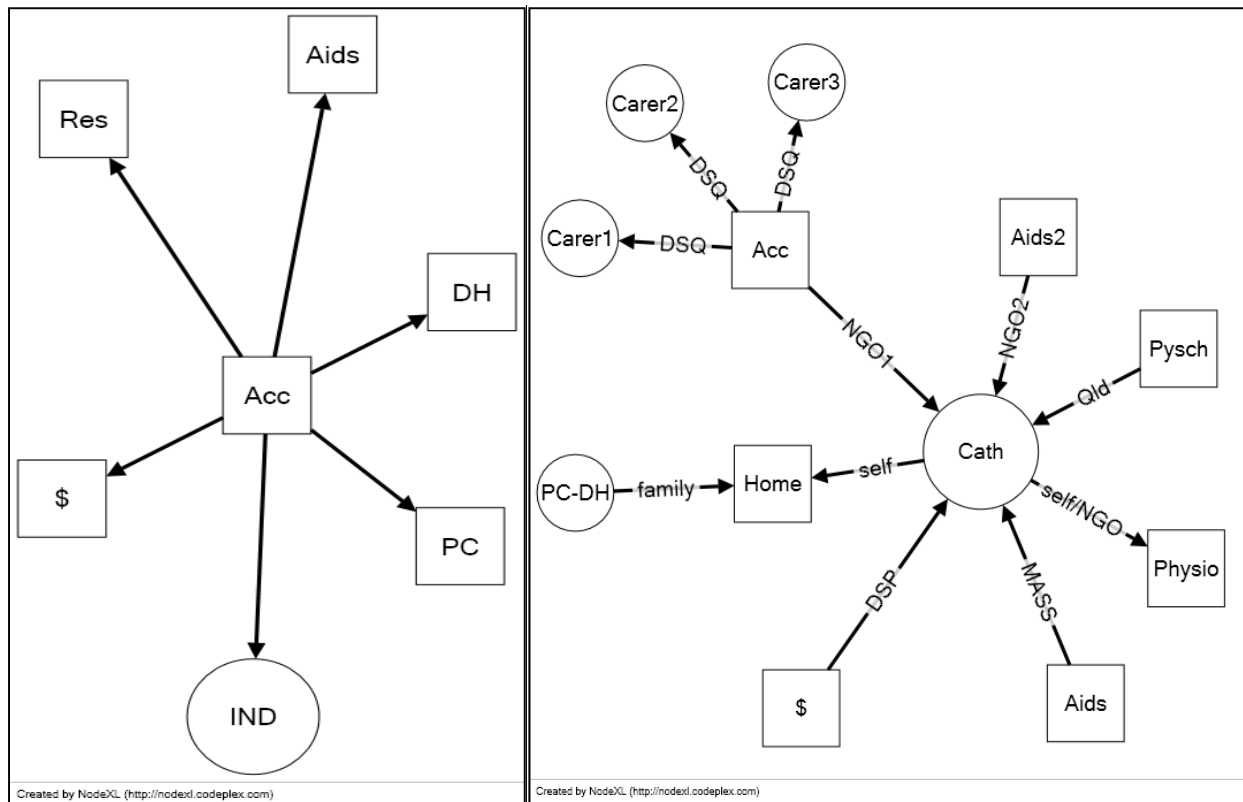
The right-hand side of Figure 3 illustrates the dwelling governance model with the case study of a 38 year old mother of four children, with an acquired brain injury. 'Cath' has 24 hour care in a house with two other women and three support workers, as illustrated in the top left-hand part of the figure. She lives close by to her husband and children where she goes "home" on weekends, and where her care is provided by her husband. While her dwelling coordinates her main care and support, Cath has several agencies involved in her care as evidenced in the figure by the number of services for psychology and psychiatry (Psych), two sources for aids and equipment (Aids & Aids2), and physiotherapy (Physio). However, there is referral and liaison between some of these varied organizations to reduce the problems associated with uncoordinated service delivery evident in the uncoordinated governance model. Cath is generally satisfied with her accommodation, which she perceives to be suited to her needs: "When I'm here at the house I feel pretty comfortable." She has the choice of cooking meals and inviting visitors. "And it makes you feel good. They make you feel like you're in your own home and you're a normal person. They treat you like everyone else." However, Cath also perceives a lack of choice about carers and dislikes having a male carer: "I have to go to the bathroom even though I feel very uncomfortable because he is a male. And showering, I

don't have to shower when he is on." Overall, Cath is satisfied with the quality of her current care, as expressed by her responses on the Services Obstacles Scale. Prior to her current dwelling, she had a series of unsatisfactory dwelling arrangements, initially an aged care facility upon being discharged from hospital, then at home where her husband was unable to manage, then another provider which she disliked due to poor care. While she would prefer to be home permanently, this choice is not possible due to resources and family relationships. Financial resources are also a difficulty. Cath's husband has insufficient funds to manage the household, and the additional expenses incurred to provide for her. As a result, Cath is now in receipt of the government Disability Support Pension which she finds inadequate: "If I don't get any more money from Centrelink to help fund what I'm doing at the moment then I can't recover or get any better." This is also reinforced in her strong agreement to the statement "Lack of money to pay for medical, rehabilitation and disability related services is a major problem" from the Service Obstacles Scale. Cath also perceived there were "very few resources in the community" for her problems.

This case study illustrates some of the strengths and weaknesses of the dwelling based governance model. The coordination of care and support through the organisation meant that there was little concern by Cath and indeed the quality of the dwelling facilities and how it is run makes it a satisfying experience. However, she did perceive a lack of control over the carer in relation to having a male carer on some shifts. The issue of finances also was raised as a critical element to ensure success.

User coordinated governance model

In response to the disability rights movements and ideas about active users of public services, a fourth model for disability governance has been widely promoted, namely, services are defined and managed by the person receiving care. This model is illustrated in the left hand side of Figure 4 with the arrows of coordination moving outwards from the individual, and is thus the reverse of uncoordinated governance model. Alternatively, a family member can act on behalf of the individual, where this model starts to blur with the caseworker governance model. The rationale and potential strength of this model is that the individual has control and autonomy over their care and support needs and is regarded as the one who knows best what they need. As a consequence, they can shape the package of services and their timing to their personal aspirations. To enable this individual-based coordination, funding is ideally provided to the individual to cover a range of services. This is evidenced in policies of direct payments in England (Blyth & Garnder, 2007; Glasby, et al., 2009; Priestley, et al., 2007) and Australia (Fisher et al., 2010), self-directed care in England (Prideauz, et al., 2009) and the planned NDIS in Australia (Productivity Commission, 2011). Alternatively, an individual budget may be provided to the individual, but managed by a third party, but the individual has nominal control over its spending, perhaps within dictated guidelines, such as in the English personalised packages of care (Leece, 2004, 2007; Needham, 2011b). The location of accountability for finance and quality of care is located at the individual, which can be both a strength, but also a unwelcome burden. Another benefit of this governance model is that it promotes a market for care and support, which in idealised market conditions promotes service innovation, responsiveness and choice. On the flip side, the marketisation of care is also a key weakness as markets can fail to develop or provide services, especially where profits are not viable (Greener, 2008). Such market failure is particularly pertinent for people living in regional areas where a threshold of services users is unlikely to be reached. Another weakness is that the lack of coordination of services may lead to

potential difficulties. While the allocation of management control to the individual enables autonomy, it also means that the individual assumes responsibility for setting up the care arrangements and funding usage. However, as evaluation of the English direct payment scheme has revealed, the successful acquisition, coordination and management of an appropriate direct care package depends substantially on the availability and capacity of the individual and their informal support networks (Blyth & Gardner, 2007). If inadequate resourcing is provided to the individual, this model can individualise the systemic failure and lead to blaming the individual for their situation. In short, governance failure in this model can occur because of market failure in care services, an inability of the individual to manage their funds or to operate as a rational actor, perhaps due to a lack of awareness of available services from which to choose, and indeed a lack of funding with which to purchase adequate care (Table 1).

Figure 4: User coordinated governance of care and support
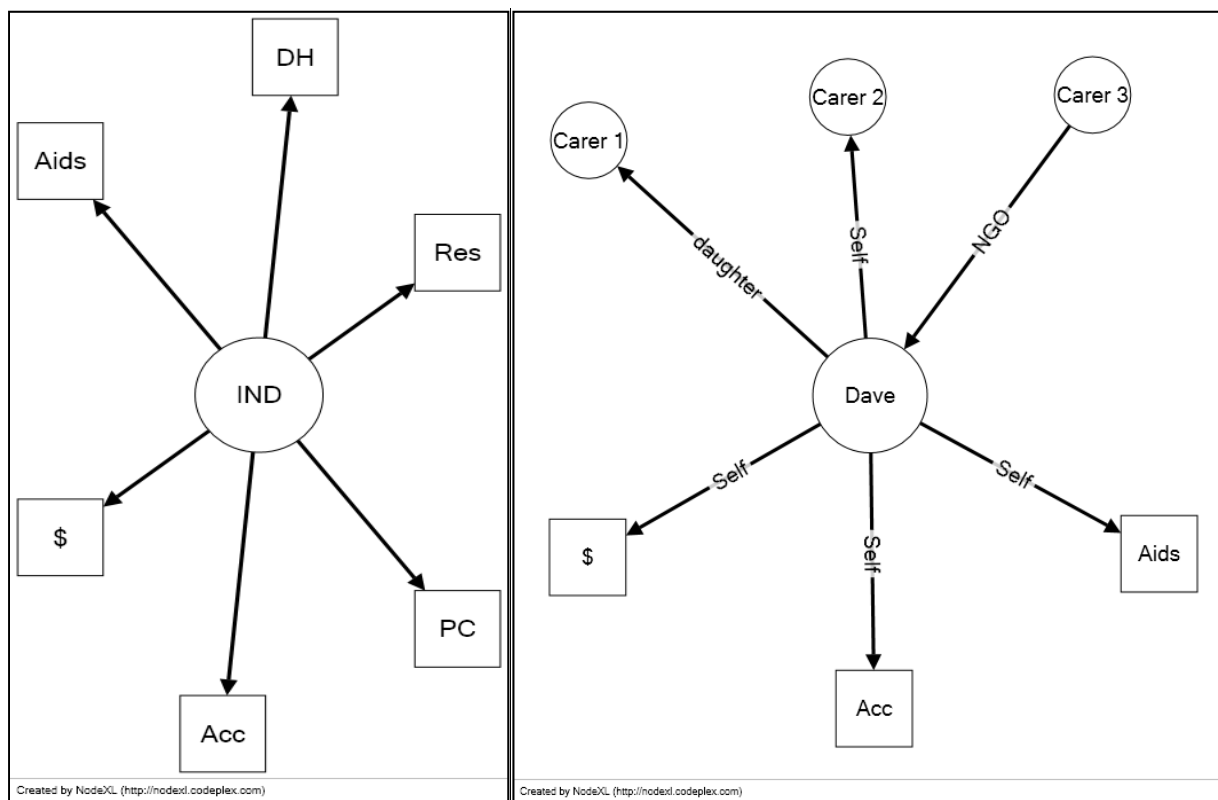
The person-centred/individual coordinated governance model of disability services is illustrated by the case of 'Dave' a 57 year old male, diagnosed with motor neuron disease three years previously (see Figure 4, right hand side). Dave is divorced and has a daughter who contributes to his personal and domestic care (Carer1). He lives in his own home with a live-in 24/7 carer who provides the majority of his personal care and support needs (Carer2) and receives personal care for showering three days a week from a NGO financed by a government personal care package (Carer 3). He personally employs Carer2 directly from Thailand. He pays for their return flight to Australia, wages, board and lodging for three-months and then flies them home again, then employs a new Thai carer. In this example, Dave specifically chose these care arrangements after finding the options available on the Australian market inappropriate for his needs. His previous experience of carers provided by a

NGO was that care was not provided at a time he desired: "I like to have a shower before about ten every day. … I don't really want to sit, especially in summer until three o'clock for someone to come and shower me that day and then, seven o'clock one morning and then half past four the next day." Dave then decided that he wanted a live-in carer, but found that Australian options were too expensive, involved having three rotating carers a day who may not be needed for most of the time, and ultimately there was "just the lack of available services and the willingness of people to come in". In short, self-funding care provides Dave with flexibility to meet his own care needs, as well as calmness and companionship. He is in control. This is also reflected in his decision to purchase an electric wheelchair rather than borrow from a NGO: "we chose for convenience to buy…I probably have about five thousand dollars worth of equipment I purchased myself, only for the ease of picking something that was just right". However, this would not be possible without significant financial resources. Dave purchases his services from a disability pension from private insurance, savings obtained by selling his business, and remortgaging his house, which he describes as "eat[ing] my house."

This particular case study demonstrates clearly that the user coordinated governance model of care and support provides good outcomes for people who have the capacity to organise, direct and finance their service needs. They are in control and determine what they want, when and how. However, the example also illustrates the possibility that the market does not necessarily provide these services, in that in Dave has had to import carers, with new questions for employment and immigration policies.

Conclusion: Deploying governance models as analytical tools

The articulation of the above conceptual governance models for care and support is designed as an analytical resource and regarded as a work in progress. In this concluding section the intention is to clarify the objective of this model development and signal possible directions for the use of this work for policy and empirical analysis.

It is quite clear from the above case studies, that reality is more complex and messy than the conceptual governance models. As indicated, the models act as ideal types to highlight key differences and to aid conceptual analysis of their relative merits. Real situations can easily involve elements from more than one of the four governance models. This is not necessarily a weakness of the models, as they can aid analysis of an actual situation for where potential governance failure may occur. Moreover, the models assist policy researchers and developers to avoid the hubris of seeking a single perfect governance model. All approaches have pitfalls. Rather, it is about balancing competing elements. Indeed, Jessop (1998) acknowledges as much. Governance models involve a tension between co-operation and competition, openness and closure, governability and flexibility, accountability and efficiency. These competing tensions are evident in the governance models outlined earlier. Too much flexibility and choice for the individual may result in too much complexity, uncertainty and unmanageability on behalf of care providers, and vice-versa. Too much accountability for delivery organisations to government may undermine efficiency in services, or responsiveness to service users. Too much competition in a market environment may result in lack of communication and coordination between different service providers servicing the one person. Caseworkers and disability dwellings can act as gatekeepers and withholders of information from individuals and undermining their choice and voice. However, one thing is common across all models. If there are not sufficient financial resources to fund the necessary care and support,

regardless of source, no model will work. A related finding of this analysis is that pooling of financial resources is much more likely to facilitate disability service governance than separate fragmented streams.

There are, however, limitations to the conceptual analysis of disability service governance above. Consideration has not been given to the nature of the organisation or person providing care, whether it be informal by family and friends, or formal by organisations, or whether the organisations are state, not-for-profit or for-profit. The various strengths and limitations of these must be considered separately.

In addition to there being no one perfect governance model, it is also important to observe that some models may be more suited to different individuals than others. People with high level cognitive abilities are much more likely to be willing and able to manage their own care using the person-centred/individual coordinated governance model (Blyth & Garnder, 2007; C. Glendinning et al., 2008).

Apart from the conceptual analysis of governance models, the models and their visual representations also provide an analytical tool for empirical work. Clearly, empirical case studies could be categorised into the dominant model in place (or using some hybrid where necessary). Such categorisation can seek to determine to extent to which each model is in existence. More importantly, is the linking of actual case studies to measures of governance success and failure, such as the use of Service Obstacles Scales. Further research might consider measurements of unmet need, quality of life, poverty or social exclusion, and personal satisfaction and happiness. This will assist in assessing the actual success of models. However, in acknowledging that some models are more suited to different types of people, empirical research may seek to examine how individual characteristics and situations are related to governance success/failure and satisfaction with care.

The visual representation of disability governance is a further analytical tool that we envisage can be further developed. In the case studies in this paper, we have included only certain types of services that disabled people may utilise. For example, we have not visually included transportation, advocacy, information provision, nor support services to (informal) carers. Inclusion of these could be done. Visual representations could also aid analysis by generating metrics such as the number of organisations (i.e. square nodes) and individuals (i.e. circular nodes) involved in providing care and support, the number of service coordinators, the number of services/providers being coordinated for each case and the number of edges connecting the individual. Such diagrammatical metrics could be utilised for quantitative analysis. Mapping care and support arrangement over time is another potentially useful use of the visual representations of care.

Moreover, these methods can also be utilised for regional and international comparative research to compare and contrast the patterns of disability governance in different locations and relate this to macro-level outcomes, such as poverty, unmet need, satisfaction, and social, political and economic engagement. Indeed, this is a task we are currently developing.

In the end, a conceptual focus on governance returns to questions of meta-govermnance, which Jessop describes as "the organization of self-organization". It involves "the design of institutions and generation of visions which can facilitate not only self-organization in different fields but also the

relative coherence of the diverse objectives, spatial and temporal horizons, actions, and outcomes of various self-organizing arrangements (1998, p. 42). Conceptual engagement with the governance of disability must return to ways in which wider processes and practices can generate disability governance that works as defined within those very processes. This is indeed a task not only for government policy, but for service providers, disable people, their families and friends, and others with a vision for what might be possible.

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Notes

[1] See for example, Bevir (2011), Newman (2001, 2005), Rhodes (1997) and Kjær (2004) as well as the Blackwell journal *Governance.*

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[3] We acknowledge that Breda et al (2006) have previously delineated three 'models of long-term care for disabled people' which respectively focus on the individual, the family informally supporting the individual and the organizational provider providing formal care. While there are some similarities to our work, their rationale for delineating models is different to ours. They delineate by where the focus of the services lies, rather than the locus of coordinating activities. Further, we have no family model, and their organizational model is split in our work into caseworker and dwelling models.

[4] The use of the open-source program NodeXL to generate the Figures in this paper is acknowledged. Details about its use can be found at http://nodexl.codeplex.com/ and in Hansen et al (2011).