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When Care is left to roam: Carers' Experiences of Grassroots Nonprofit Services in Ireland.

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Abstract

Increasingly countries are turning to nonprofit organisations to provide health and social care, particularly for people with disabilities. Alongside this change, debates continue about how states should manage the relationship with such organisations. Should features of the old-style "welfare" model be retained? Should aspects of the "new public management" model be chosen to measure the impact of the work? Yet others argue that grassroots organisations should form the basis of a service provision system. In the context of these debates, Ireland serves as an interesting case study of the system of care that can emerge when the state operate a "relaxed control" approach. This paper takes the perspectives of users themselves: family carers who are accessing services for a disabled adult child, to examine the effects of this approach on the ground. We show how geography played a central role in shaping these experiences, and discuss how we can learn from the Irish context. Rather than arguing for narrowly defined contractual measures, we conclude by proposing a renewed focus on relationship building with the aim of effective system operation, in the future of care services.

Key words: voluntarism, nonprofit, caregiving, disability, Ireland, organisation.

Introduction

Increasingly, the effective operation of health service delivery in general, and services to people with disabilities in particular, is dependent upon nonprofit organisations. This trend has emerged after years of political and ideological debate about the potential for voluntarism to resolve their fiscal and administrative problems, with regard to the provision of services (Salamon et al, 2003). Our paper is therefore written at an interesting time of change, and addresses debates regarding the relationship between state and voluntary organisations relevant to this change. To assist such debates, this paper examines a unique case study of Ireland to show the local level implications of a particular service model on family carers of people with disabilities. Ireland is seen as an important site of study, given that the Irish state has an unusually long history of drawing on local, relatively autonomous, voluntary organisations within a relatively decentralised monitoring framework in the provision of care services.¹ Moreover, particular features of the Irish service provision landscape parallel those being called for by advocates of a ‘hands-off’ provision model.

In this paper, we examine the implications of Ireland’s hands-off decentralised model on the local landscape of service delivery, and explore what lessons can be learned. At the heart of the landscape of care provision are the families of people with disabilities. These groups continually use a whole range of services offered by nonprofit providers, including day care,

¹ For a detailed history, see Barrington, R. (1987) *Health Medicine & Politics in Ireland, 1900-1970*. Institute for Public Administration, Dublin.

occupational training and nursing care. In this paper, we focus on family users, echoing authors who argue for the importance of hearing and understanding the concerns of stakeholders, when researching social policy implications (e.g., Morgan et al., 2002). We draw on narratives of family carers, as they describe their experiences of accessing such services. Interviews were conducted with 25 such people (C. 1-25) in suburban hinterlands in North County Dublin and neighbouring County Kildare.

Our paper is structured as follows. First, we introduce current debates regarding the role of nonprofit organisations in the provision of care services. Next, we present a history of state-nonprofit relationships in Ireland, in order to contextualise our case study. We describe the implicit model of care provision in Ireland, to set the scene for our study. We then present our empirical findings, in which we examine perspectives of family carers and their experiences of Ireland's "geographies of care". Our findings address the burgeoning interdisciplinary interest in the voluntary sector as both the subject and context for inquiry within health geography by examining the complex ways in which Ireland's 'hands-off' approach is experienced at the ground level. Finally, we return to examine international debates in light of our case study and consider an alternative model by which state-nonprofit relationships might be managed. Rather than argue for a move toward state-centred welfare provision, or New Public Management-style monitoring, both of which are seen as problematic, we suggest that an 'experimentalist' model, as identified by Sabel provides a new alternative.

State - Nonprofit Relations: Some Views

Across the Western world, states are increasingly unable to cope with providing health and

social care services. In response to this, many governments are using nonprofit organisations for service provision (Salamon et al, 2000). Van Til (2007) for example, reports how such changes are taking place within the Dutch sphere, with Kramer (1990) noting similar situations in Germany, Belgium, Switzerland, Austria and Italy. Questions are emerging regarding how best to manage relationships between these sectors. Here, we outline some relevant topics of debate, focusing on issues of centralization, accountability and autonomy. Two points are important to note. First, while these issues are not exclusive to state-nonprofit sector governance, they emerged as particularly important and relevant in the context of the data collected for this study. Much more could be written about state-nonprofit relationships, but given the limited scope of this study we wish to particularly focus on the features that relate to our data. This is in line with best practice in qualitative research, in which pertinent themes emerge from the data and are allowed to guide the subsequent analysis (Blumer, 1954). Second, while service provision is commonly discussed in terms of well-known, simplified “models” (e.g. New Public Management or Welfare State), in practice, service delivery structures vary across countries in more complex ways than indicated by such models. Each country’s service provision typically draws on features from across a range of models (Arnold, 2007), and so there is little value in adhering to the above delineations. Instead, we focus on the following features, which remain central to current debates.

Centralisation: One key topic of debate which emerged involves centralisation. To what extent should services be coordinated from a central locus? Under the model of state-centred welfare provision used by a number of countries, decision-making is centralised in order to achieve an even spread of standards across a range of organisations. The idea is that access

to services would be more equitable (De Vries, 2000). Similarly, with regard to the information that is available to users at the local level, it is often useful to have a centralised point of access (Hood, 1991).

Centralised provision of state services has attracted much criticism however. One critique involves an inherent “claim to universality” which persists in centralised welfare provision (Hood, 1991: 8). In other words, the idea that one size fits all, or that one form of governance will suit the myriad different types of health provision, is seen to be problematic. Critics argue that remote decision makers have little understanding of what is happening at the local context, and that this is reflected in poor decisions and inappropriate choices (Ackroyd, 1995). In the UK for example, many Primary Care Trusts have expressed disappointment in their inability to pursue locally defined agendas (Wilkin et al, 2002). For Le Grand (1999), NPM-style reforms in the British NHS had minimal success, which was partly to do with the fact that centralised control was retained.

For some, therefore, decentralisation of public services is the best way forward, and offers a means to overcome “the limitations of centrally controlled national planning by delegating greater authority to officials working in the field, closer to the problems” (De Vries, 2000: 197). It also allows organisations to be flexible, responsive and represent diverse improvements in the way in which mental health services are delivered;

Because they are based in communities, voluntary groups are active at a local level and their agendas are driven by the priorities and needs of people at the local level, rather than by

national strategies and policies directives. This means that they can understand the needs and priorities of their local areas and can respond with innovative ideas and provide flexibility for the development of these ideas and action. (Department of Health and Children, 2006)

In other words, local organisations can truly understand the needs of their clients and can provide more targeted, appropriate services without being subject to more abstract, disconnected policies and directives that are formulated at the national level.

Accountability: If a state is engaging a nonprofit organisation to provide particular services, how should the organisation demonstrate its accountability to the state? The question raises the issue of monitoring: the introduction of clear measures of progress and impact, and ensuring that these are met. Authors tend to agree that some form of monitoring is vital in order for states to gain a good service from the organisations to which they are entrusting their service provision (Arnold, 2007). Even with its problems, countries introducing tighter monitoring models under “new public management” (NPM) initiatives, have seen increased financial accountability in areas of procurement, for example (Hood, 1991).

However, authors note how close bureaucratic monitoring can hamper organisations in carrying out their work, given the inherent slowness that this brings (Barnett and Barnett, 2006). Close monitoring can tie up organisations and prevent them from carrying out their work of service provision. Where tightly proscribed contracts have been used, voluntary organisations risk losing flexibility, innovation and dynamism (see for example, Salamon et

al. 2003). Under recent NPM initiatives, contract-style outsourcing has begun using quantitative, calculable metrics of “impact” requiring tight specification of what is to be carried out, and the expected results of the work, by the provider. Critics argue that these types of performance measurements are inappropriate for health and social care (Thomas and Davies, 2005). A further issue is that the process of negotiating contracts and adhering to monitoring procedures often works in favour of larger over smaller organisations (Barnett and Barnett, 2006).

Autonomy: Related to the above issues is the question of autonomy. How independent should service providers be? Under the “welfare provision” model for example, much control remains with the state, as services are provided through the public sector. This has both advantages and disadvantages. On the one hand, it is seen to bring about greater professionalism, and more transparency with regards to funding. On the other hand, Noonan et al (2008) argue that command-and-control types of welfare governance constrict agencies’ abilities to adapt to rapidly changing conditions, to increase their capacities where needed, and to tailor their responses to diverse clienteles.

Of particular interest in this paper is the idea, shared by many critics, that service provision needs to become more autonomous. In response to issues such as those raised above, new and autonomous organisations are emerging, which tend to operate independently in a ‘bottom-up’ fashion, responding directly to the needs of users. Much of the policy literature from across developed countries describes the potential for such autonomous organisational forms to effectively address historical problems in service provision (Milligan and Conradson, 2006; Salamon et al, 2003). For example, Van Til (2007), citing cases in

Germany, France, Egypt and the US, points to new groups of nonprofit organisations emerging which claim to provide a more community-focused service provision, which are “more people-friendly than those emerging from bureaucracies” (p.37).

For some, the sheer size and inherent bureaucracy of traditional welfare provision models are inherently unequal and preclude diversity of choice (Popay et al, 1999). They have also been criticised for “hierarchical forms of delivery in which knowledge meant power and in which users had little say or control” (Ibid: 3). Feminist and anti-racist groups, such as women’s health groups and Saturday schools for black children have long been arguing for alternative, often separate” forms of welfare based on smaller, autonomous organisations (Ibid: 11). These agencies reject the search for universality, in favour of celebration of diversity and difference.

Autonomous organisations are therefore seen to have the inherent potential to be more innovative and flexible, than larger, state-wide bureaucracies. The idea is that these organisations are not constrained by dictates from the centre, but offer pluralistic, people-driven approaches to service provision. Their emergent nature enables them to be developed for particular subgroups existing in a range of local settings. Such organisations also provide a space for debate and dialogue on how particular social problems should be resolved.

We have described above some questions that underscore state-nonprofit relations, around the areas of accountability, centralisation, and autonomy. These are key concerns for those involved in designing or maintaining service provision models in any country context. From the above overview, we see that certain features are implied as being best for users of

disability services. It appears that a system in which local level organisations are in charge of offering services, are enabled to make their own autonomous choices with little interference from the centre, and remain free of the burden of continuous monitoring and reporting, would be best. Such a system would enable services to emerge that fit the specific needs of users themselves, and organisations would be able to redesign these services in a fast and flexible way. In this paper, we take a closer look at this somewhat utopian vision. We examine one country context, that of Ireland, and ask whether the implied benefits for users are within reach. Before describing the findings, the following section briefly paints the context of service provision in Ireland, in which the research took place.

Background to nonprofit contracting in Ireland

Ireland serves as an interesting case study in light of this debate. Ireland has one of the world's largest nonprofit sectors (representing 11.5% of non-agricultural employment in 1995), second only to the Netherlands in Salamon et al.'s 22 country study (2000). Here, geographically-dispersed, local nonprofit groups have for years dominated health and social care provision for people with disabilities. Given its strong legacy of small-scale, decentralised approaches to health and social care services, Ireland may serve as an interesting study region for other countries in which this form is being considered as a potentially useful model of service provision.

Since the establishment of the Irish State in 1922, *the principle of subsidiarity* has been important in guiding State-nonprofit relations. This principle involves the State adopting a *hands-off* approach; only needing to step in as a last resort when other service providers, such as the parish, local community or voluntary organisation, are seen to fail. The fledgling Irish

state had few resources to support such provision, and saw the Catholic Church as potentially being able to take on this responsibility. Interestingly, at the outset, there was a scarcity of religious orders willing to undertake this work but after considerable grants of land and buildings were promised in the early 1950s, the Catholic Church obliged (Ryan, 1999: 121).

The formalisation of this relationship can be seen in the terms of the Health Act, 1953, which established Section 65 grants² to nonprofit organisations providing ‘similar or ancillary’ services to those of the State (Donoghue, 2007). This funding model provides global grants directly to the agencies on the basis of the previous year’s financial outturn, proposals to improve or expand services, and the availability of finance generally (Ryan, 1999). As long as the outcomes that were originally proposed by the service provider are shown to have been met by the end of the year, there is little transparency on how money has been spent. Amounts spent on staff, transport and care remain opaque. Moreover, there is typically little connection between the size of the grant and the numbers cared for, the category or the degree of disability (C&AG, 2005). The inherent freedom granted to recipient organisations remains a characteristic of the Irish system today.

With such a relaxed system, service providers are by and large able to carry on their work immune to criticism. Historically, the lack of monitoring benefited the State in that they

² Section 65 of the Health Act, 1953 allowed the health services (known as the health boards from 1970) to provide funding to voluntary organisations for health and related purposes. ‘Section 65 funding’, as it became known, became the largest source of funding for voluntary and community organisations in the state and health boards took a broad social view of the type of services that these organisations should provide. They have since been renamed Section 39 grants, after the Health Act, 2004.

could depend on the church to carry on with the business of disability provision, without taking upon itself burdens related to the ‘problem of the handicapped’ (Department of Health, 1960). Since then, from the mid-1960s onwards, there has been a significant increase in secular nonprofit agencies, particularly parent organisations, providing similar services. However the system of devolved responsibility for disability provision has remained and typically requires few checks and reporting systems.

Despite recommendations from a White Paper (Department of Social, Community and Family Affairs, 2000), which advocated jointly developed service agreements, these still read like high-level, somewhat abstract guidelines that merely describe the ideal principles of engagement, in broad terms. In practice, these do not specify details of how to structure relationships. Monitoring is thus rare and, where it is in place, is poorly carried out. As O’Donoghue (2007) notes, the White Paper exists “more in the realm of rhetoric than practice” in today’s service provision (p. 15).

Evidence of this lenient relationship has come to light recently with a national audit of nonprofit disability service providers, by the Comptroller and Auditor General (C&AG). Its report (2005) found a widespread failure among organisations, many of which were secular, to provide audited financial statements or disclose levels of executive pay. The audit of 42 organisations found that 12 groups did not file accounts for 2003. In particular, one large organisation which received €288m during 2000-2004 had not provided financial statements for these four years. Furthermore, according to the same report, visits to three Health Service Executive (HSE) regional offices found that the information captured from their monitoring processes was not systematically used for evaluating service provision.

In short, we conceptualise Ireland’s model of care provision as one of “Relaxed Control”.

The features of this are summarised in Figure 1 below:

FIGURE 1 ABOUT HERE

We see from our overview of debates in nonprofit relationships with the state, that Ireland’s model contains features that might be seen as desirable for those calling for change to current systems of service provision. It is at once decentralized, with relaxed accountability demands, and high levels of autonomy for service providers. We might expect that users would experience a personalized, flexible and responsive service under such a “relaxed control” model. Ireland thus serves as an interesting and timely case study in the debate over greater or lesser statutory governance, and the degree of regulation and monitoring of the nonprofit sector. To unpack this debate further, it is important to move beyond the abstract state level and examine the implications of this service model on service users themselves. From our study, we can see how the relaxed model of governance seems to affect actual service delivery.

Findings: Implications on today’s geography of care

This section examines family carers’ particular experiences of gaining access to services. Geographical issues emerge as central, in relation to access to care. For families, the implications of the service landscape outlined in the previous section were evident in their appraisal of the service providers. All caregivers were caring for people with learning

disabilities³ aged between 18-30. The services in their jurisdiction originated as grass-roots parents' organisations and grew over time to provide essential services for adults with learning disabilities in their vicinity. They operate in areas with increasing young commuter populations, thus are under similar pressures to provide services to this expanding population. Both areas have also seen a decrease in the availability of "natural supports" in the form of friends and family, given the rise of dual-earner households in the area. The organisations operate in an autonomous manner, responsible for their own management and budgeting, and for designing their care service. These organisations remain representative of the model of service provision in the Irish landscape, described above. It is also worth noting that this case-study was conducted during a period of significant economic growth, characterised by the 'Celtic Tiger'. While this period has now passed, leaving providers with new constraints under which they operate, the timing of the study nonetheless demonstrates that the findings below do not necessarily relate solely to budget constraints.

No Information: No Input

At the outset, families complained about a gap in information coordination. Information was not forthcoming in advance, leaving families often unable to plan for the future:

³ Learning Disability is a problematic and complex concept given that its meaning and interpretation can vary; generally it is defined as having long-term impaired intelligence and social functioning (Department of Health, 2001).

She wants to do courses, you know, she wants to better herself. So I was just told we have to wait until March to know if there is a place for her. So I said, 'you're actually telling me that you don't know if she's going to be accepted or not?' and now, if she isn't accepted, where do I go from there? (C. 20)

Here, we see the confusion that accompanied the lack of available information. This information was not forthcoming from the service provider largely because the number of places available was unknown at the time the parent approached the organisation as well as a reluctance to take on new clients because of the potential resource demands involved. This lack of flexibility brings to mind a monolithic non-responsive organisation, a characteristic of a centralised top-down service, rather than the grass-roots type of model the system is supposed to deliver.

The carers claimed that the information deficit was a major problem. Carers argued that such a lack of information on what was available felt like a smoke-screen for the service users:

It's almost like a smokescreen. There are services there but nobody tells you. There's not that much you can do. You can't fight the system, you're just at their mercy really. (C. 3)

The above quote also evokes the helplessness inherent to the lived experience of dealing with an opaque, non-responsive organisation. In addition, most carers reported that many of the decisions made about services for school leavers with disabilities were made without their input. Generally carers felt that the information that was available was limited to what each autonomous organisation considered to be relevant, rather than a community-wide focus.

This is redolent of organisations being stuck in silos, meaning they rarely engaged with other bodies outside of their disability remit.

This silo mentality was also evident in the recent Comptroller report (2005) which found that information systems within the HSE (in relation to their disability services) were generally underdeveloped, making it difficult for managers to obtain a clear picture of what was taking place in the various organisations operating across the country. It appears, therefore, that our respondents' sense of frustration at an opaque system, in which information was difficult to obtain, reflects the findings of this report.

Access - Getting a Place

Interviewees spoke about how their caregiving experiences were strongly influenced by the control that particular organisations had over the landscape of care provision. In a given geographical area, it is the individual, autonomous organisations that decide what services they should offer. These organisations also decide who should be allowed to avail of these services. This manifested itself in a number of problematic ways. First, many of the carers argued that they found it difficult to get a place with the service provider in their designated area due to the autonomous gate-keeping capacity of organisations.

A second problem involved the fact that even when people were allocated a place, it was these were often unsuitable. In some cases, people whose particular disability doesn't 'fit' the service provider's remit, find themselves outside of the system, unable to obtain the help that they need:

We applied to St. [Pauls] and... they weren't too keen on taking him because he hadn't got Down's Syndrome. And they were saying we could put him out in the ordinary school. We stood up and said. 'you couldn't put him into a normal school'. He couldn't speak. They taught him sign-language. Prior to that, he was like an explosive bomb. It was terrible. So in the end they took him. They didn't really want to take him. And what do you do if they say we don't want to take him? – keep him at home? Send him to a school and they'd ring you up and say, 'take him out of here please'. (C. 4)

In this case, we see how a young adult with profound autism was caught in a position where he had no choice in day support. In a region where the local service provider focussed on caring for people with Down's Syndrome, the carer was left with no choice but to accept an inappropriate placement. The only other resolution was to care for the child without day support at home. As another interviewee notes:

If you don't slot into their box, it's quite bureaucratic. And it's either a take it or leave it scenario. (C.15)

According to Ryan (1999), because of the autonomy of service providers, the disability has to fit into what the agencies wish to provide. If the agency does not wish to cater for that disability, the person with that disability does without: "That is what happens when a government cedes control of a service to autonomous agencies" (p. 128).

A further issue concerns the way in which organisations design their menus of service options, so as to categorise particular disabilities. Where a child has behavioural problems *as well as* a particular disability, the system has no way of catering for this situation. Carers reported implicit expectations, on behalf of the organisations that they were dealing with, that the person being cared for does not have any behavioural problems, extra impairments or health problems:

It depends again - if your child is very good, you will get respite. If your child has diabetes and a heart condition, you won't get respite. (C. 16)

In summary, we learned of three ways in which carers experienced problems due to the way particular autonomous organisations had structured their disability service. Firstly, obtaining a place was often difficult, and secondly, even where a place was secured, this was frequently unsuitable to the disability in question. Finally, where people experienced more complex issues, such as behavioural problems, organisations were often simply unwilling or unable to provide the necessary help.

Choice - Switching Between a Place

Service providers tend to operate within “catchment areas” which generally match a county boundary, and this tends to hinder service users’ ability to switch service provider. Generally, there is one service for a particular disability per jurisdiction. As noted above, if the service provider decides not to accept a person with a disability, there is often little else available in the same coverage area. This reflects a general lack of choice available to service users. Family carers felt they could either use the local service, even if it was inappropriate,

or as an alternative, be left with nothing:

They sent [Joe] home one day [for aggressive behaviour], and they rang and said don't send him in again. So basically he's never had a service since. He had just gone 18. It was basically January. I was in touch with the Health boards, they were saying, 'could we not manage to make a compromise between us and St. [Pauls]'? It didn't dawn on me, that they didn't *have* another service. In their minds, St. [Pauls] had taken him on and so that was it, he was theirs forever more. It was their tough luck and it was my tough luck. Sure eventually they were just told to take him back to St. [Pauls], you know, the very place that had thrown him out. At that stage we were expected to get down on our knees and for them to do whatever they wanted. (C. 24)

Carers frequently found that they were trapped in instances like this, with little choice, as a result of where they were living.

Moreover, carers felt that they were denied the option of going to another service provider. They argued that they often could not seek services in other jurisdictions, when they were under the umbrella of a nearby service provider. Carers were genuinely frustrated by this lack of choice and access:

If you were going with one service, they won't let you use another. Like at [St. Pauls]; he hasn't had speech therapy since

August. The speech therapist is on maternity leave. There's only one. And he's not allowed use any other service for speech therapy because he's under the umbrella of [St. Pauls]. I mean, they sent me home an information pack to work with him. But I'm not a speech therapist. I do my best but I've two other children. (C. 3)

Unfortunately, as this carer identified, if a family wants to move to another organisation, the funding allocated to the organisation does not follow the person; it stays with the original service provider (Broderick, 2009). This is because autonomous service providers are responsible for finding their own funding, and tend not to want to pass funding on to other organisations. This reflects the lack of portability in the sector. This can force carers into a very difficult situation in which they must make decisions on whether to move jurisdiction, in response to inadequate services being available where they live. This is not an easy choice and can be full of additional risk, given that they have to undergo a brand new assessment because of separate HSEA regional structures. This general reluctance to relinquish funds on behalf of service providers leads to a geographic “trapping” of families into their allocated regions

Power - Service-centred, not People-Centred

In many cases, we heard from carers that service provider organisations tend to operate to meet their own ends, and not for the interests of the users.

While they all talk about Person-Centred Planning, and they all talk the talk, when you actually go to look for a service, if you're not within their service, if what you want is not in their service, just forget it. It's actually a waste of time. (C.15)

Rather than a person-centred service, carers often felt they were dealing with a mechanistic organisation, with a conservative ethos, more concerned with the internal work of meeting the present needs of the organisation, than responding to their needs and helping them. One carer, who also worked in a care advocacy group, claimed that the disability services work simply to their own needs:

I think the services are not there to meet the needs of the community, of the carer, or the person they are caring for. It's slow, it's cumbersome, it doesn't operate to the needs of the carer, it operates to the needs of the system. The system operates it, not the patients. So it's the system working for the system, not for the people. (C. 1)

According to Osbourne (1998), these traits are characteristic of bureaucratic organisations whose mission and goals have drifted over time, such that the organisation works to meet its own needs. This concept of "goal displacement" in organisations can lead to people following a cycle where internal rules and procedures are followed at the expense of the original mission of the organisations (Merton, 1957). In Ireland, this may be related to the fact that organisations have in some cases grown rapidly in size, in response to increasing numbers of service users. For example, some day services cater for up to 400 individuals, where they have not been set up to do this. Also, disability services in certain regions have

had to confront the 'medical' focus of funding over the 'social', as a result of working in a less progressive health service area. With these service expansions and outside challenges has come complexity in organisational systems, technocratic practices of rule-following, and being swept up in agendas and pressures that often have little to do with their founding purpose. Yet, families are still asked to have faith that these systems can be reliably trusted to be attentive to the needs of people who often may be inarticulate, powerless and acutely vulnerable in their dependency on them (Broderick, 2009).

Discussion

We have seen here how the “relaxed control” model of state–nonprofit relationships can play out at the local level. In this paper, we describe just such a landscape: one in which care is provided by spatially diverse, autonomous groups. As we saw, many authors discussing the provision of public services are advocating for local, democratic and autonomous units to provide such services. However, we see in the findings that these features are not without their problems. When we add these insights from carers’ experiences to the more macro issues of lack of central control, coordinated services, or accountability, we see that there are a number of significant problems inherent to Ireland’s model.

Returning to wider debates on state-nonprofit relations, it appears that while ongoing, tightly specified monitoring has its critics, without some form of monitoring, the problems that users at the “ground level” experience, can go unnoticed. From this, we argue that while the kinds of quantitative metrics that tend to be introduced alongside NPM changes might be unsuitable, a form of monitoring that focuses on *users of the service themselves*, is essential. The problem with autonomous, independent organisations providing disability services is that

these organisations are the sole guarantors of access. Where carers are experiencing problems with the system, such as frustration with being trapped in a particular area, there appears to be little way for their voices to be heard. A system of appropriate monitoring, based on carers' concerns being listened to and addressed, appears to be needed.

Regarding the issue of centralisation, in Ireland we can see that problems persist in terms of access to information, and coordination across services. While Osborne, De Vries and other critics of centralisation argue that such a system prevents local practitioners from responding quickly and adequately to needs of users, this appears to be related to an ideal case. In any event, it does not appear to be the experience of carers we came in contact with. Nor did a decentralised system bring about better representation for diverse groups. In fact, those with unusual situations, such as behavioural problems, found themselves outside of the system, with nowhere to go. Despite the rhetoric around local organisations in the Irish context, it appears that the reality can fall short.

Finally, it appears that the autonomy of organisations can engender a reluctance or a refusal to cooperate, to share information, to transfer funding and to facilitate people moving from one area to another. Furthermore, the fact that organisations provide services to suit themselves means that users are confined to "fitting in" to the care that is being offered, and have little choice in what is offered. We see how this landscape of service provision can lead to a trapping of carers into their own geographical region. Rather than being "user-led", such services are driven by the mission of the organisations themselves.

We see how these observations contribute to debates on how state-nonprofit relationships

might be managed. As an alternative to state-controlled welfare provision or NPM, autonomous service provision is not necessarily the answer. This paper has outlined some important insights into why this is so. From looking at the specific applied aspects of service supply, demand and choice, the local autonomy evident in the Irish model can be as much a trap and a constraint, as an advantage in terms of flexibility and responsiveness.

An Alternative Model

It appears that a model incorporating appropriate forms of monitoring, where users' voices are heard, and where organisations are subject to some forms of centralised planning, might be appropriate. We are not arguing for an increase in neo-liberal style competitive contracting however. We see clearly from our interview respondents that their concerns are not being heard. It is unlikely that an even more competitive and autonomous architecture would ameliorate this problem (Marsh and Spies-Butcher, 2007). In addition, we see from the findings that a degree of centralisation appears to be needed. Notwithstanding the criticisms of hierarchical structures and centralised welfare provision, without some level of standardisation of information and service options, people will continue to be blocked from moving freely from one area to another, without the need for reassessment.

In concluding, we propose that a middle-way model be sought. The change agenda in the delivery of health and disability services indicates the need for a system based on an integrated learning process that enables effective ongoing policy development, resourcing, capacity development, and implementation of monitoring and evaluation. In reflecting these goals, an alternative framework for purchaser-provider relationships in human services has been championed by Charles Sabel (e.g. 2006). This has been coined the 'experimentalist' or

pragmatist approach, and shifts the emphasis in exchanges between state and provider from a primarily punitive to a primarily learning basis.

This broad approach has been widely tested in a variety of human services and other public policy settings in the United States including child welfare in Alabama and Utah (Noonan et al., 2008), enhancing interagency collaboration among public health agencies and private community-based programmes (Ibid.), and occupational health and safety (Liebman and Sabel, 2003). Experimental principles define an approach to the management of purchaser-provider relations that is wholly different from the structure that now governs many neo-liberal welfare states.

Under Sabel's schema, a number of decrees exist which guide the experimentalist model: firstly, basic norms – guidelines – must be both learned and elaborated in the course of practice. Reconfigured training of staff, including the introduction of mentoring partnerships is helpful in this regard. Secondly, a new conception of the relation between central administration (government or relevant department) and the frontline (staff dealing with the clients) emerges. The centre articulates general goals, provides support for the frontline, and monitors its success in vindicating the principles. Thirdly, change is incremental, to enable the process of learning (Noonan et al, 2008).

Discussing the practice of monitoring in the Irish context, Arnold (2007) argues that future changes in service provision must include “a greater level of accountability and a demonstration of effective management”, and argues that nonprofits in Ireland generally require improvement in this respect (p. 78). In terms of the tools used to determine best

practice, and monitor relationships, Sabel's approach proposes to reverse the direction and substance of the exchange between purchasers and providers and to move away from fixed rules, towards enabling the continuous evaluation of possible changes in the rules:

Accountability thus requires not comparison of performance to a goal or rule, but reason giving'. (Sabel, 2006: 14)

In this model, evaluation of a service provider is carried out with the input of other agencies in a process of ongoing mutual reflection. Here, we would draw on the findings of our study to argue that monitoring must incorporate a user-focus, with voices of carers themselves being heard. For Sabel then, monitoring is continuous, or nearly so, rather than occasional or episodic: and it is less interested in outcome measures than with diagnostic information – information that can redirect the method of provision (Marsh and Spies-Butcher, 2007).

Often when service providers fail to follow the rule in command-and-control systems, they stand to be immediately penalised. In pragmatist systems, inability or unwillingness to improve or respond to change at an acceptable rate triggers initially increased capacity enhancing assistance from the centre. Repeated failure to respond, even with assistance, is, however, likely to bring about penalties for the offending service (Sabel, 2006). As we noted in the context of debates on whether organisations should operate in an autonomous capacity or not, in order for the benefits of decentralised, independent service provision to emerge, such autonomy must be facilitated by appropriate structures. For example, while local organisations can bring benefits such as greater representation for diverse minorities, and more rapid response to user needs, this must be supported by the wider system.

Of course, in shifting towards an experimentalist architecture, much remains to be done to work out particular details in relation both to the specification of outcomes and the design of an appropriate governance structure. As we have shown, different countries operate in their own specific contexts, and we would not advocate an unproblematic “transposition” of this model onto the Irish landscape of care provision. As Arnold (2007) notes, there is huge diversity across countries with regard to welfare provision. In considering these options, it is important to remember that no country is in a position to completely reinvent its welfare provision model, should it so choose. Legacies of previous patterns and systems of service provision persist, for example, the UK’s history is one that ranged from an older “command and control” model of state welfare provision, to a market-“liberal” model of contracting between state and service provider (Salamon et al, 2000). Any abstract formula, such as Sabel’s model, must always be carefully adapted to suit.

Conclusion

This paper has identified the experiences of family carers in the context of the Irish care system characterised by a local, ad hoc service model. By explicating the geographical implications for service users on the ground, it is possible to see that without the tighter standards and structures in place, the service landscape is characterised by significant geographical variation in access and types of services available, and limited user portability. Rather than advocating more command-and-control governance of the nonprofit sector, the findings suggest that a middle-way between tight accountability policy design and a hands-off approach by the state could be met. An ‘experimentalist’ health and social care system, as advocated by Sabel is proving very successful in a range of different welfare settings. In

particular, with disability and care services, such a model promises a more flexible and partner-driven approach towards local service delivery.

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