The disability rights movement has achieved significant recognition of the rights of people with disabilities across the world, resulting in disability service and disability discrimination legislation and increased pressure upon governments to meet their obligations in relation to the inclusion of people with disabilities in all aspects of society. An important strategy of the movement has been to reframe the debate about the experience of disability from one of individual pathology and inevitable service reception, to one of societal disadvantage and oppression and the need to ensure that society meets its obligation to disabled citizens. However, the notion of services providing the “solution” to many social and other barriers remains strong within government and bureaucratic circles, and the recognition of inadequate resourcing of the service sector has meant that disability advocacy groups are locked into debates about increasing resources for services. This paper argues that particular strategies for reforming the disability service sector can and do bridge the divide between the discourse of rights and that of service provision, in particular those which highlight self-determination as a means and an end. Significant sector reform is recommended, building on initiatives in Australia, the UK, the USA and Canada, as an alternative to the resourcing of pilot “models” and “capacity building”, which are the current strategies of service development in NSW.

Background
This paper sets out a number of issues, the starting point for which is a perception of major problems with the current system of delivering specialist services to people with disabilities in NSW. This perception comes from having worked within this system for the past sixteen years, the last decade of which has been combined with intensive study of disability issues and, to a lesser extent, of comparative service systems across the world. The issues raised in this paper represent the central theme of a PhD thesis which I am undertaking at the University of New England, Armidale, hence the length of the paper. In order to present and deal with a specific argument, some issues are mentioned but not explored to any great extent. I have attempted throughout to highlight where theory may be useful in analysing what I regard as a system that ultimately fails the test of achieving positive outcomes for people with disabilities, but have concentrated in this paper on practical systems problems and potential solutions. Thus, for example, whilst the thesis will highlight a particular theoretical approach, and outline a methodology prior to analyzing the issues, this paper will focus on the issues, and mention the theoretical approach in passing. I have also made statements about what I have observed of the system, and for the purpose of stating a broad issue I have not yet sourced documentation to some of
my observations or claims. Part of the research methodology of my PhD thesis will be to conduct literature reviews and to interview key officers within government and non-government agencies, in an attempt to evidence my claims, and I will expect that in time some claims may be modified upon closer inspection.

**Introduction**

The theme of “inclusion” has particular resonance for people with disability, as the experience of disability since the Industrial Revolution has largely been one of marginalization and oppression. It has been generally accepted that the goal of assisting people with disabilities to participate in society and enjoy opportunities for inclusion to the same extent as other members of the Australian community underpin both the Disability Services legislation (Commonwealth 1986, and NSW 1993 – complementary legislation in other states) and the Commonwealth Disability Discrimination Act (1992). The NSW Disability Services Act (1993) guides the funding and provision of services and supports to people with disabilities in that State, and is administered by the Department of Ageing Disability and Home Care (known hereafter as DADHC or “the department”). Supports to people with disabilities are provided either directly by DADHC operational services (but limited to people with intellectual disabilities), or contracted out to a large and growing number of non-government and private agencies. The Commonwealth State Disability Agreement (CSDA) of 1993 has resulted in the Commonwealth taking responsibility for the funding and provision of employment services to people with disabilities, as well as some of the responsibility for funding advocacy services nationwide. This arrangement can be problematic for individuals who wish to make the transition from State-funded programs to Commonwealth-funded programs, but that issue will not feature in this paper.

This paper takes a brief look at some of the problems of delivering services that will deliver outcomes of participation and inclusion for people with disabilities, and argue for an approach which combines the energy that has been devoted to the promotion of rights in this area with advocacy for a radically altered service delivery system.

**The Rights Approach**

The disability rights movement has been organised and active worldwide for some decades now, and has had success in many countries promoting the human and civil rights of people with disabilities as the primary issues that need to be addressed. However, within the general population, the dominant imagery of
people with disabilities is a portrayal of impairment and incapacity, as worthy of assistance yet ultimately not contributing in any significantly positive way toward the (economic) prosperity of the state. This is evidenced by the depiction of people with impairment in the media, which rarely if ever follows the conventions of terminology set out for journalists to follow, and which continues to use, for example, the wheelchair as a powerful symbol of tragedy and incapacitation. Another powerful and abiding, commonsense notion of disability is that of the perennial service user, and the accepted norm for the experience of disability is to be a recipient of services and to have one’s life routine largely set by the availability and location of service providers.

This stands in sharp contrast to the expectations of many people with disabilities, and the goals of the disability rights movement, as expressed in the large body of knowledge and scholarship which can be collectively known as the “Social Model” of disability. This Social Model has identified traditional thinking about disability as belonging to an “Individual Model” of disability, a mode of understanding that places the cause of all disadvantage experienced by people with disabilities within their individual conditions. There are a number of Individual Models of disability that have influenced general opinion about the experience of disability. Possibly the most influential and powerful group that has defined and theorised disability in recent, modern history is the medical profession. The resulting medical model,

... has guided and dominated clinical practice with the resulting assumption that both problems and solutions lie within people with disabilities rather than within society (French, 1994, p.4).

This assumption has meant that the medical and “helping” professions have been both assisted by, and complicit in, the development of the “personal tragedy” model of disability. This regards people with disabilities as victims of great misfortune who daily eke out a fractional existence, and tends toward protective services. The personal tragedy model leads to images of people with disabilities as either passively coming to terms with a traumatic experience that will forever limit their activities, or as bravely and triumphantly overcoming these limitations by great mental or physical effort. Either image powerfully reinforces the idea that it is the disability itself that causes the limitation, and hence the suffering, not how opportunities in our society become suddenly and dramatically reduced once a person is described as having a disability.
The Social Model has sought to redefine the experience of disability in terms of its social impact, reducing the focus on impairment, and thus on the provision of services to remediate issues and problems faced by people with disabilities. Abberley (1987) has argued that the experience of disability is primarily one of oppression. In many ways disability is a category of people who are systematically excluded, abused or discriminated against in the same way as people of colour, women or those with differing religious beliefs. However, Abberley has argued convincingly that disability oppression is particularly insidious because it is constructed as a lack, or as somehow “less than whole”, regardless of the other human characteristics attributed to a person. In essence:

(f)or disabled people the body is the site of oppression, both in form, and in what is done with it (Abberley 1987, 14).

Abberley’s contribution is significant because, while he is clearly politicising the experience of disability, he is also arguing that impairment itself is a social product, citing industrial accidents, political decisions and the promotion and consumption of products that are detrimental to human health (Abberley, 1987).

**Rights-based Services**

The Social Model has highlighted the lack of access for people with disabilities to opportunities for inclusion in the community, and has taken an overtly political stance against physical, institutional and attitudinal barriers that prevent participation on an equal basis with other community members. The principle strategy has been attempting to overturn, through the enactment of anti-discrimination legislation, policies which attempt to segregate or otherwise limit opportunities for people with disabilities (Barnes 1991), as well as the development of principles and standards that need to be met in the community in order for equal opportunity to be available.

Despite its broader political agenda, Social Model writers are not silent on the issue of specialist service delivery to people with disabilities. However, their critique of the way that services are currently delivered is largely negative, seeing them as an extension of the medical model and replicating practices which necessarily view the individual as a pathological problem, and do not adequately take account of the social disadvantage that in effect “disables” the person. This continues the practice of treating the person and not addressing the social and political issues. There is also some negative critique of broad policies which are broadly viewed as progressive, most notably the policy of providing care in the community. As French (1994) has indicated, a policy which expected a
community to be able to provide what was necessary to people with disabilities, after having developed its infrastructure for over a century with the expectation that people with disabilities would be excluded, is at best naïve and at worst an example of choosing the less costly option at the expense of positive outcomes. In terms of how services are delivered, Social Model writers have a clear preference for support arrangements which honour the choices of the individual, and which are used as a necessary assistance to enable people with disabilities to pursue their life goals and to participate in a range of activities that are commonplace to most members of the community.

Social Model writers, in particular Priestley (1999) and Finkelstein and Stuart (1996), believe that existing “community care” legislation is limiting in the way it allows for supports to people with disabilities to be delivered. The control over services and funds by either health or welfare departments, and their emphasis on “care”, means not only that the citizenship and participation ambitions of people with disabilities are not adequately addressed, but the administration of such services becomes a barrier in itself. Social Model thinking discredits the whole notion of a “special”, service system, and instead insists that services and supports generally available to the public be made accessible and available to people with disabilities. The insistence on maintaining a parallel, “special” system helps to perpetuate the attitudinal barriers against people with disabilities, and does nothing to progress their claims to rights. Priestley argues that the movement is more concerned about outcomes rather than means, about equality of participation in general community life, rather than with specialist service provision, and that therefore:

… the achievement of real and positive outcomes for service users will depend not only upon participative delivery structures but also upon effective community development work, collective self-advocacy, campaigning and political struggle (Priestley, 1999, 192).

Priestley stresses the linkage between how service quality, and quality of an individual’s life, are assessed, and the type of service that will be delivered. Up until now health and welfare authorities have been more concerned to target individual need, rather than the citizenship and participation aspirations of people with disabilities as members of the their local communities. Much of the impetus from bureaucracies has come from a requirement to cut costs and ration scarce resources (Priestley, 1999).
Services that operate in accordance with the wishes and aspirations of people with disabilities, and in broad agreement with the critical focus of the Social Model, need to address the collective social barriers, as well as meet the individual’s personal needs. Priestley advocates for a radical shift in the types of needs assessment that are currently provided, and a recognition that services for people with disabilities must be properly integrated into the wider community service system, so that collective barriers might be broken down and broad aspirations such as employment and education might be achieved. He illustrates the place of disability services thus:

(Priestley, 1999, p.,175)

Finkelstein and Stuart point out that disabling barriers exist at all levels of our society, and that they must be broken down. Breaking down the barriers has to be seen as one of the core activities for services that support people with disabilities. The way that cultural change must take place, including legislation. This is a starting and not an end point, as it can only set the legal framework within which people must then challenge the commonplace cultural assumptions of what disability is, and what people with disabilities need. One of the fundamental principles of all services to be established according to Social Model is that they must be empowering. The notion of “specialist” services helps to promote the idea of people with disabilities as not belonging to the community. Finkelstein and Stuart (1996) advocate a shift to assessment processes that focus
on citizenship goals, and a broad lifestyle focus for service delivery within the existing community services system, as a way to translate the Social Model into practical supports. They advocate the need for a change to a “disability culture”, where the perspectives of people with disabilities become part of the overall community consciousness, and where their needs and opinions are validated at the same level as those of other groups and individuals. The reform of the service system has, then, a crucial role to play in the development of this new culture.

**The Service Sector in NSW**

Much of the Social Model scholarship, especially that which has critiqued the service system, has emerged from the United Kingdom, where some changes have occurred over the past decade which are significant, and which have acknowledged the citizenship and rights of people with disabilities in the rationale for change. However, the transition of service provision from within institutions to settings in the community, has followed a similar path in the UK, the USA, Canada and Australia, as well as in other European countries. The passing of the Commonwealth Disability Services Act in 1986 (DSA) represents the foundation for reform in this country. The Act itself expresses quite explicitly the rights that people with disabilities should enjoy, and indicates that funded services should be working toward assisting people with disabilities to achieve these goals. The Commonwealth State Disability Agreement was negotiated in 1993 to share the responsibility of funding and administering disability services across both States and the Commonwealth, and complementary legislation was passed in the States to mirror both the aims and the general approach of the original DSA. The NSW Disability Services Act (1993) has also developed a set of standards, the NSW Disability Services Standards, which guide services toward practices that can generally assist people with disabilities to achieve goals that are in line with the rights expectations of the DSA.

Whilst the Social Model has in recent years been acknowledged and had some influence upon the way that services are conceived and delivered in the UK, this is not the case in Australia. The main reference point for the delivery of services has been the “Community Living Principles”, which are a handful of strategies, theories and ideologies which were targeted originally at institutions, firstly developing practices which addressed the health and educational needs of those within total institutions, and then identifying alternative models and arguing against the use of institutions in any circumstances. Throughout much of the 1990s the approach of Social Role Valorization (Wolfensberger 1983) was adopted by the Commonwealth administration as the guiding principle for
services. There are some similarities in the approach of SRV and the other Community Living Principles with that of the Social Model, especially in the recognition that the problems faced by people with disabilities are largely socially constructed, and require significant changes in social relations for the problems to be alleviated. However, it is significant that the principles that have underpinned the Disability Services legislation in this country are primarily service-based approaches, with the result that the legislation assumes the continued existence of service as the primary locations in which people with disabilities will experience more positive outcomes. This has some effect when we are talking about the process of de-institutionalisation, which was the context for the development and application of these principles, but has less impact on achieving widespread change in community attitudes, the amelioration of physical space and the reform of social institutions to be inclusive of people with disabilities.

Despite the significant reform that was ushered in by the DSA, and the passage of time since its enactment, the service delivery system has, to all intents and purposes, remained the same. It is true to say that in recent years in NSW there has been a huge increase in the resources expended on specialist services for people with disabilities, which is also reflected in the rapid growth of the government department which has responsibility for the allocation and delivery of these services, the Department of Ageing Disability and Home Care. There has also been a significant change in the extent to which services are delivered in the main by government services, with the growth in contracting out services to the non-government sector, and the change in culture amongst disability services to one of competition and growth. There has also been a level of experimentation with different “models” of service delivery, as a response to the centralised planning put in place by the NSW DADHC, which has since embarked upon processes of regionalisation and regional capacity building. This latter strategy is a process of expanding the service system as a response to the diversity of need across the state, and has led to a wide variety of different service types and models being established, often differently configured and defining eligibility differently to meet specifically identified local area needs.

The main strategy to counter allegations of inertia and irrelevance within certain programs, for example day programs, has been to develop newer models which respond directly to identified need (i.e. need identified by the department) and which demand an operationalisation of “best practice” by those who wish to provide the service. Precise specifications of what needs to be achieved, the measures by which equity is to be ensured, and the broad means by which
outcomes are to be arrived at, are provided in Expressions of Interest, and agencies invited to respond with a view to providing services in this manner. The aim is clearly to engender innovation whilst maintaining efficiency and effectiveness through the precise targeting of supports, and is the clearly articulated strategy of the department in addressing the need that clearly still exists within the community for people with disabilities. There is nothing inherently wrong with this strategy, especially as we shall see later a needs exists for increased infrastructure prior to sector reform. But the assumption that it will, of itself, solve current system problems or meet the expectations for self-determination and choice that are built into the Principles of the Disability Services Act 1993 is, I believe, wide of the mark.

Some Systems Problems
There are some clear problems that exist for people with disabilities in NSW who need specialist supports to be able to participate actively in community life:

- the disability service system itself is fragmented, a great variety of funding and service delivery programs which makes it difficult for people to navigate;
- a lack of cohesion and cooperation between services to provide a consistent approach to the support of an individual, and services not being set up to address an individual’s changing needs as they age and develop;
- there are inequities and anomalies within the system, for example in the provision of day program activities for people with intellectual disabilities, where a person who is eligible (of a certain age in a particular year) is entitled to a package of support worth up to $16,000, and person older may receive less support in the same program because their entitlement is only averaged at $9000 per year;
- the goals of inclusion of people with disabilities necessarily span the areas of responsibility of more than one government department, and currently there are problems with the intersection between DADHC and government departments (for example the Department of Housing, Health, Correctional Services), as well as the need to make inroads into the provision of public transport, access to education and family services, and a whole range of activities and opportunities that do not fall under the auspice of any government department or agency;
- the growth of agencies as a result of responding to Expressions of Interest has led to some service users attending a range of different supports
which are essentially under the control of one agency, contrary to the
principle of the Disability Service Act that aims to avoid this type of
control.

It is worth at this time revisiting what is meant by “needs”, and to discuss how in
fact the whole premise of the strategy of regional capacity building has missed a
crucial step if in fact the actual needs, or issues, of people with disabilities are to
be successfully addressed.

At the beginning I articulated the main issue for people with disability as the
realisation of their human ambitions through adequate opportunity to
participate in the social world, and therefore the need for the social world to
adapt and grow with the recognition of the need to include people with
disabilities. A very swift analysis of the brief description of the current service
system above will indicate that needs are still very much articulated according to
impairment type and according to the requirement for care and support, rather
than aimed at overcoming the discrimination, exploitation and oppression
experienced as a matter of course by people with disabilities. This may be
explicable by the enormous responsibility they have in attempting this wholesale
systems change, but surely should come under scrutiny by the department
charged with making the DSA happen. The activities of advocacy bodies over
the years have become much more focused on achieving social change, and there
is perhaps a growing acceptance within the community that this is their role,
whereas the role of services if to once more “treat” the client.

Associated with this assumption is the continuation of the relationship within
disability services, where the provider is the “expert”, the “professional”, and
their knowledge is the treatment of the impairment in specialist ways. The
department supports the system of service providers, ensuring that they attain
basic standards of care and support through system’s accreditation tools, which
value indicators like policies and procedures and tools such as formal assessment
and planning processes. The regional capacity building strategy is aimed at
providing a range of different service types to meet a broad variety of need, yet
the premise of placing a person with a disability in a certain type of service still
predominates over the strategy of building supports that are individually
tailored around an individual. The limited patchwork of services provided to
meet a variety of need, expressed generally rather than individually, and the
continued expectation that a combination of service types will provide for the
range of needs (guaranteed by individual planning within each service)
continues to place stress between services and service user in terms of the
expectations of meeting need (eg group home placements are at a premium, so people accept them regardless of the compatibility amongst the individuals who live there). In summary, a good outcome for a person with a disability in the current system is that they receive a handful of different services, from different providers, to the extent that their days and weeks can be defined by their attendance at or support by these services.

From the point of view of people with disabilities who use services this is not the ideal situation, and puts pressure on both formal support relationships with services, and social and family relationships, which are increasingly being utilised as the basis upon which specialist supports are added. The over-reliance upon unpaid carers to prop up the system, which puts pressure and strain on family relationships, makes these relationships unequal and unnatural because of the total commitment to one family member by the carers. As well as placing strain on the physical health of carers, and upon the relationships within the family unit, over-reliance upon carers can serve to undermine the confidence of an individual who is cared for through a combination of lack of entitlement to basic services (to achieve basic civil rights and opportunities), and a sense of gratitude to the carer and a passive stance not wishing to cause offence or trouble by making demands. This difficult situation is made all the more difficult by the trouble that people with disabilities have in obtaining the type and level of support they need, at the time they need it. The sense throughout the sector is that there are currently inadequate resources to meet everyone’s need, so rigorous eligibility and priority criteria are put in place to act as a gatekeeper to these scarce resources and services. This means that, for example, carers have to go to increasingly drastic lengths to secure the right and opportunity for funded supports. Strategies that are openly suggested to carers include placing their family member in a respite facility, and refusing to pick them up; and insisting to departmental officials that they will perpetrate violence against the family member if the current living arrangements continue.

In the course of my studies I aim to analyse these sorts of dynamics, which I believe further undermine the possibility of a cohesive service and support system, that utilises both formal (and thus expensive) service delivery and the natural (and thus virtually cost neutral to governments) supports of family and friends. At this point my belief is that the system will continue to inadvertently manufacture need for its formal services, whereas reform in the way that the whole system is configured has a chance of working better for individuals and their networks of support, thus eventually reducing the reliance people have on expensive, formal services.
In addition to the need to make the system work better, there is a requirement to better resource services and approaches that represent a positive change. One positive aspect of the regional capacity building strategy is that it values new models of service delivery, and is prepared to fund them. However, increasingly new approaches to disability support are holistic in nature, and require a much more cohesive service and support response in order to be successful. One such approach is the “Life Course Approach” (Priestley 2003), which focuses on the differing requirements and ambitions of people with disabilities at different stages in their lives, and acknowledges the various social, cultural and familial influences which shape the individual’s experience of impairment and disability, and which might need to be addressed as part of support arrangement for that person. The implication of this approach is that services should take much greater account of these personal and individual factors when determining the supports that are required, and that supports need to be much more personalized if they are to be effective. Achieving such a personalized approach is difficult when the system is being built from the top down, when the needs of people with disabilities are being generalized and provided according to broad population demands.

Alternative Systems Approaches

The previous section has looked at a few of the problems with the current service system in NSW, as part of a justification for why an alternative approach to delivering services should be considered. This section will look briefly at how other jurisdictions are looking at reforming their disability service systems, and will begin by briefly stating the system problems that those strategies aim to overcome.

In the United Kingdom the problems identified with the system of community care provided to people with intellectual disabilities are similar to the issues identified in this paper in NSW. They include poor service coordination, poor planning for young people, little choice or control by service users over many aspects of their support, as well as lack of resources and over-reliance upon family members and carers (Valuing People 2001, 2-3). Similar problems have been experienced in British Columbia, but a significant criticism there is the way that the service system has fostered dependency and eroded the capacity for support to be provided within the community through the use of natural networks:

The current system is built predominantly around services. Too often regulation, policy and practice intended to support people with
Developmental disabilities still reflects a custodial perspective that views people with disabilities as “deficient” and needing to be “fixed”. Their gifts and contributions are rarely seen and even more rarely appreciated. An unintended consequence is that community capacity, the idea of “neighbours helping neighbours”, has been diminished by the unswerving focus on services (A New Vision for Community Living 2002, 42-43).

The UK, under some pressure from lobby groups of people with disabilities, and acknowledgment at least of the goals of the Social Model and its focus on lifestyle, choice and supports that enable rather than totalise, has had legislation for 7 years that enables people with disabilities to receive the funds earmarked for their support and arrange and organise their own supports and services through the employment of attendants. The Direct Payments Act (1996) enables people with disabilities to purchase services, which are then held accountable on a commercial basis for the delivery of support. Some analysis of the take-up of such arrangements indicates that people with intellectual disabilities have not benefited to the same extent as those with physical impairments from these arrangements because of the difficulty they have had in demonstrating they are both “willing” and “able” to administer the funds and organise the supports. However, the “Valuing People” paper (2001) has required local authorities (who organise supports and services for people with disabilities, and are responsible for the funding) to resource individuals with disabilities to a much greater extent to make informed choices about the support they receive. The paper highlights four key principles that the government wishes to address in services for those people who have intellectual disabilities, namely:

- Legal and civil rights
- Independence
- Choice
- Inclusion

(Valuing People 2001, 23-24)

A principal strategy to achieve these goals is to institute person-centred planning and to resource this process through the provision of information supports to people with disabilities and their families. The ownership of the plans by the person with disability, and their capacity to clearly articulate needs that are answerable to a person’s wishes and aims, should help to drive change within support services and make them more accountable directly to the person.
The mechanism of funding the individual directly will now be more available to people in the UK given the supports that will be in place to resource the decision-making of individuals with intellectual disability. This is a significant mechanism which has the capacity to deliver to people with disabilities much greater autonomy and actual control over the supports that they require. This represents a significant difference in approach to that of NSW, where the “purchaser” is the department. Equivalent authorities in the UK are regarded as “funders”, and the purchasing of services is done either by the service user or a specially commissioned service. In British Columbia a different approach is being tried, namely community ownership of the funding and allocation process, as well as a range of innovative methods for distributing funds and making ownership of support arrangements much more the domain of those who require the supports in the first place. The Community Living British Columbia Authority is to be established, having as its membership people with developmental disabilities, families and carers, all of whom have been nominated from their communities. It will take on the role of deciding how resources are allocated, whilst the government will have the responsibility for providing those resources.

Both of these initiatives are in their very early stages, so it will take some time to evaluate their effectiveness. But both have recognized that the problems inherent within the disability service system lie beyond just the mode by which individual supports are delivered by agencies, and require a broad systems change to address them.

Foucauldian Analysis

The purpose of this paper is to set out some problems and to suggest some solutions. However, as it also describes some of the research agenda for a thesis, which will require a more sophisticated analytical framework than mere comparison of similar systems of operation. I intend to critique the systems approaches taken in the UK and in British Columbia, as well as to continue to look at the system in NSW in greater depth.

I have chosen a Foucauldian methodology for my analysis, as I believe that it has the capacity to critique systems accurately, and is in keeping with current trends in disability studies. In recent times the Social Model has turned away from an exclusive concentration on the broad, political or “disability” issues, and scrutinized the way that impairment issues have a strong political element. Bill
Hughes (2002) has characterized this as progression from the initial denial that ‘(t)he ontological essence of disability is a physical or mental impairment or a biological ‘deficit’ or ‘flaw’ that limits what disabled people can do’, through a restatement of disability as a social and political issue, and finally to the statement that “impairment is social and disability embodied” (Hughes 2003, 60-66). Disability studies continue to throw light, not only on the lived experience of impairment and its social and political construction, but also how such analyses can be applied to the general population to look at how similar forces can shape the lived experience of other people. Foucault’s focus on “bio-power” is a significant contributor to such debates. Other research topics and themes of Foucault that are relevant to disability studies include the growth of the domination of modern medicine, sexuality and discipline, as well as the growth of the asylum in *Madness and Civilisation* (Foucault 1988).

One aspect of social organisation that Foucault was concerned with toward the end of his life was that of “governmentality” (Foucault 1991). Whilst seeking to describe the formal mechanisms within society that contribute toward its control and governance, this approach also takes account of the social and cultural practices that enable populations to be identified and controlled, and helps to shed light on the part that is played by the various actors and agents within any scenario that has as its aim the provision of public assistance to individuals or groups. This concern with how populations are governed assists us to come to terms with the different rationales for action and motivations of the diverse players within a complex disability services system. The theme of governmentality has not been utilised to any great extent within disability studies. Tremain (2001) has used it to look at how in general techniques of power are used upon the bodies of people with disabilities to effectively govern them and the limits of their actions. My approach will be more concerned with the specific governance of people through the provision of services, more limited on the one-hand, yet within some systems quite all pervasive given the assumption that people will spend much of their life in specialist services. One of the important observations that can be made up front using this lens to view the service system through, is that governments have a role to respond to the needs of their population, but that their motivation for particular action will be to ensure the good governance, and thus control of that population overall. It is quite rational, then, for there to be tension between those who demand resources and the government department charged with distributing them. This represents an opportunity for DADHC to articulate their role in resourcing the sector, without the current level of expectation on it to “solve” the issues
confronting people with disabilities – this is better handled at the level of individuals and groups of people with disabilities.

The approach I am taking highlights self-determination as a key indicator of success in the system. The DSA allows this to be a legitimate performance indicator, but the scrutiny is on the system and the way that services are resourced to make this happen. Such an approach also helps us to look afresh at the role that the movement of people with disabilities worldwide has played for so many years, and continues to play, confronting social institutions with their pervasive discrimination and challenging the general population to think afresh about the impact of impairment on an individual’s life.

**Discussion**

I will briefly explore the theme of governmentality in disability services, utilizing an analytical tool that is currently used to explain the mechanisms that make a process of funding an individual work. The diagram on the next page describes a service arrangement, by detailing the various roles played by a variety of actors. It has been devised to promote the superiority of arrangements which allocate different roles to different individuals and agencies, such that conflicts of interests do not occur. But it can be used to determine which individual, agency or department has the most control in any of the relationships that need to be developed and managed within the entire network of arrangements. It is useful because it can quickly demonstrate at which point in the relationships the person who uses the services is in control. If independence between agents within the support relationship can be achieved, this along with the greater control afforded to the service user at every point has the capacity to deliver outcomes that value the choice and preference of the service user.

From the point of view of the system and the department these support arrangements are what can govern the individual and limit the demands made upon the resources of the government (governance). From the point of view of the service user they will determine whether or not the goals he or she has articulated are going to be met or not, and to what extent they will be able to participate and be included in the activities of their choice (individual choice and ambitions). From the point of view of service providers it gives clarity about what to do, and where their accountability lies (service viability and growth). The real motivations of each agent are laid bare, and negotiation can continue amongst them openly and honestly.
The actual roles of the department will be changed to some extent in an arrangement that aims to provide maximum control to the service user. Firstly, its role is to facilitate these relationships, and to this end the provision of individualized funding, allowing the direct employment of staff by the service user must be an option. Secondly it plays the role of the funder of the arrangements, and this is represented in Stage D. Finally, it has an important role to play in the evaluation of service quality, which it will continue to manage through its contractual arrangements and its accreditation systems.

Figure 1. The EMPRISE Circle.
The advocates for individualized funding and self-determination see the divesting of roles to various agents, independent of each other as a strength of the arrangement, from the point of view of diverting the maximum power and control into the hands of the service user (Dowson and Salisbury 2000 and 2001). There are immense strengths to the flexibility of service delivery that such funding enables, and I have previously illustrated successful outcomes for people who have made use of these arrangements (Bleasdale 2001). The principle of self-determination is present in the Disability Services Legislation, as part of the statement of the rights of people with disabilities that services should be striving for. It also accords with the demands of Social Model theorists who want services to be much more accountable to the individual, and be used to facilitate participation and inclusion.

One possible criticism of such a complex arrangement is that it could lead to confusion and inevitable tension amongst agents, and instead a simplification of arrangements must be achieved to enable cohesion and successful outcomes. Put briefly this is a tension between those who see diversity within an arrangement as a positive, and those who see it as a confusing negative, which has the potential to disempower the individual and render their support network ineffective. The tension that will be to some extent inevitable, given the number of officers, agents, service providers as well as family, friends and advocates of an individual within any one support arrangement, is viewed as a positive, an opportunity for dialogue and negotiation, as well as an admission that until the views of the individual are sought and alternatives there is no such thing as a pre-fabricated solution based on knowledge of their impairment type.

A significant question is raised for me at this point, and no doubt in the minds of those who are following the argument with some concern. Are we “selling out” to the powers that be which promote economic rationalism, the inherent superiority of contracting out, the inevitability of global economic forces impacting on the our sovereign government’s ability to make decisions about spending scarce funds on social programs – in short to the highly idealistic project, masquerading as an inevitable consequence of the march of time and progress, that is late industrial capitalism? Are we throwing in the towel and abandoning the fight for an alternative system, that is born of the needs of individuals, and which seeks to make economic systems subservient to the will of democratically represented populations?

At first glance the proposed reforms may appear to sell out to these forces, and in fact I accept that some of the strategies that will be useful in promoting such a
strategy are based on the real argument that it will take contracting out to its obvious next phase, and make services grow through their competence in meeting client need, rather than their attractiveness to funding bodies who prefer large agencies – undoubtedly a form of competition. And it is true that many advocates of individualized funding are very comfortable with the ideology of free markets and free enterprise, and are keen to use any entitlement of public funds to invest and seek out innovative business ventures, rather than just spend the funds on traditional support arrangements. However, my interest in the topic has stemmed from an original critical position, which portrayed the pursuit of individual empowerment through funding as antithetical to the broad project of achieving rights for all people with disabilities, and the articulation of a Bill of Rights (Bleasdale, Crumpton, Hardaker and Tomlinson 1996; Bleasdale and Tomlinson 1997). I was a welcomed participant in discussions that took place electronically across the world in the late 90s, although it was generally accepted that my position was critical of IF as utopian ideal. My participation in an international conference in Seattle was also welcomed, and I presented papers critical of the lack of such arrangements in NSW, but also strong positions on the desirability of union award conditions in IF arrangements, and a piece that foreshadowed research that looked at the outcomes of IF supports in terms of the control and power they conferred to an individual with disability. Through intense dialogue with some of the principal proponents of IF and Self Determination, as well as through conversation with people with disabilities who have utilized such supports, I have become more supportive of it as a broad systems approach to the delivery of services, and am now seeking to understand it from a more level critical standpoint.

In the course of my reading and dialogues I have recognized a strong social citizenship motivation on the part of those who are pressing for these reforms across the USA, Canada and the UK. For some advocates, particularly the family members of people with intellectual disability, the granting of individualized funding arrangements is sees as a natural progression from the other Community Living principles that they lobbied for in the 60s and 70s, and which have not realized their full potentials due to the inability of the system to cope with outcomes related to self determination. I have also perceived a good deal of fit between the articulated wishes of people with disabilities for their supports to be delivered in ways they wish, according to their terms, and often utilizing supports that they instigate and manage themselves, rather than contract out to agencies which in the past have shown little willingness or ability to be flexible.
Conclusion

One of the important factors of this system is that it does not claim to be an “ideal” system. Rather its rationale is that it is a replacement for a system and an approach that is now outdated and needs to be reformed urgently. The goal of a reformed system that builds supports around the individual should not be regarded as an “ideal” or any sense of a “natural progression”. What is called for is an overturning of assumptions about how people with disabilities (and this could be extended generally to those who receive some sort of assistance through the welfare system) are served by the support agencies that have been meant to address their needs and respond for the past 15 years. When Standards and accreditation have not achieved an outcome focus, what is required is scrutiny of the actual mechanisms of the system, and reform at that level will inevitably lead to change in the way that agencies are forced to respond to the needs of their “clients”. The tensions explicit within each of the various relationships in this circle of support are expected and planned for, whereas the expectation currently is for a seamless delivery of supports negotiated through a cohesive hierarchy where all parties respond in an orderly fashion. The broad goal of “empowerment” is achieved to some extent throughout all the arrangements, because of the opportunities for choice and decision-making, and the honouring of those choices by a more responsive system.

Despite a growing sense that the current service delivery system does not work, advocacy to date has focused upon the inadequacy of available resources to meet the needs of people with disabilities in Australia, and specific practices within services that do not meet the good practice standards expected under the DSA. There has not been much scrutiny of the way the system is run by DADHC, possibly because that department has control over what aspects of the sector get monitored and how. The main thrust of my studies will be to describe the systems that are in place throughout the department, and the extent to which these result in outcomes for individuals with disabilities in line with the expectations of the DSA.

The potential for a common goal provides an opportunity, in my mind, for cooperation between groups which in the past have expressed significant differences in arenas such as how advocacy should be delivered. It provides, importantly, a definite, positive change for which to lobby, instead of focusing solely on the failures of a government department, or of the system, or of the level of resources which have resulted in the lack of suitable and successful supports for people with disabilities – whilst at the same time retaining the status
quo in expecting the department to come up with all the answers and “purchasing” the solutions from an unhelpful distance.

In conclusion I believe that the point of convergence between the rights agenda and the progressive service agenda is the need for systems reform, focusing first on the way that funds are made available to support individuals with disability, and later at the level of actual service delivery by agencies. The goal of a reformed service system become the inclusion of people with disabilities in community, and their participation in all the activities that members of our society are entitled to. This follows the rights agenda not only in terms of its aims through the outcomes it proposes to achieve, but also through the means, by implementing at every level the principles of choice and self-determination.

**Bibliography**


